# PERCEPTIONS OF CANCER RISK

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# ABSTRACT

This thesis examines perceptions of risk for bowel cancer. Nationwide bowel screening will be introduced in the UK in April 2006. To achieve maximal uptake of screening it is essential that the population is sufficiently motivated to attend, and perceived risk is recognised as being the 'motivational engine' behind preventative behaviour. Studies 1-3 used data from the UK Flexible Sigmoidoscopy (FS) Trial to examine perceptions of bowel cancer risk. In Study 1 an optimistic bias was found. Being male and older were associated with lower perceived risk, while having a family history of bowel cancer, poorer subjective health, more symptoms and higher levels of anxiety were associated with increased perceived risk. Study 2 explored how perceived bowel cancer risk compared with risk status defined by findings at the FS test. A modest relationship was found between subjective and objective risk. Study 3 investigated how well the five factors identified by Weinstein (1984) explained the variance in perceived risk for bowel cancer, but found that only 8% of the variance was explained. The qualitative interviews in Study 4 found support for Weinstein's framework and provided information on how better to operationalise the framework. These measures were used in Study 5 and the variance explained increased to 18%. Study 6 was a randomised controlled trial assessing whether giving people simple, accurate information of bowel cancer and its risk factors i) increased knowledge of bowel cancer ii) reduced the optimistic bias associated with symptomatic status, family history, age and gender, and iii) increased interest in attending bowel screening. The intervention successfully increased knowledge, but failed to reduce optimistic beliefs or to increase interest above the high levels found in the control group. Future research should consider influences on perceived risk not accessible to self-report and how people draw conclusions from generic risk information.

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## Perceptions of risk and comparative optimism

### 1.1. Perceived risk and health behaviour

Perceived risk plays a pivotal role in understanding health behaviour. At a minimum, people must recognise that there could be a possibility of contracting a disease before personal action to protect health or prevent disease is likely to follow. It is therefore not surprising that assessment of perceived risk is ubiquitous in health psychology research, not only as a component of almost all models of preventive health (e.g. the Health Belief Model (HBM), Rosenstock, 1974; Protection Motivation Theory (PMT), Rogers, 1975; the Precaution Adoption Process, Weinstein, 1988), but also as a 'stand alone' variable in empirical research (e.g. McCaul, Branstetter, Schroeder, & Glasgow, 1996; Vernon, 1999; Aiken, Gerend, & Jackson, 2001; Honda & Neugut, 2004).

Perceived risk is often seen to be the 'motivational engine' behind health protective behaviour. The more vulnerable an individual perceives himself/herself to be, the more likely they are to engage in a range of health behaviours. Perceived risk has been associated with mammography screening (Aiken, Fenaughty, West, Johnson, & Luckett, 1995; McCaul et al., 1996), intention to take a faecal occult blood test (Weller, Owen, Hiller, Willson, & Wilson et al., 1995), blood pressure assessment (Avis, Smith, & McKinlay, 1989), influenza vaccination (Cummings, Jette, Brock, & Haefner, 1979), and engaging in HIV preventive behaviour (McCusker, Stoddard, Zapka, Zorn, & Mayer, 1989). If we cannot motivate people to engage in screening programmes, or carry out other health-protective behaviours, health cannot be maximised. It is therefore crucial that we have a thorough understanding of this construct.

### *1.1.1. Origins of perceived risk in health psychology*

The concept of risk perception in health emerged from work carried out in the 1950s by health service psychologists in the US. It grew out of concerns about the failure of large numbers of eligible adults to participate in tuberculosis (TB) screening, despite the service being free of charge and available locally in mobile screening units. Perceived susceptibility to TB was identified as being a key factor in explaining this (lack of) preventive behaviour. It was conceived as being composed of two components: the first was the recognition that developing TB was a realistic possibility, and the second, that a person could have TB in the absence of symptoms (Hochbaum, 1958; Strecher & Rosenstock, 1997).

### *1.1.2. Conceptualisation of perceived risk within social cognition models*

The early findings have been influential in most of the models of preventive health (e.g. HBM, Rosenstock, 1974; PMT, Rogers, 1975; Theory of Reasoned Action, Fishbein & Ajzen, 1975; Precaution Adoption Process Model; Weinstein, 1988), within which perceived risk is regarded as a key motivational determinant. An early meta-analysis of 46 studies using the HBM found that in 81% of the studies, perceived susceptibility was a significant predictor of behaviour (Janz & Becker, 1984), pointing to its central role in understanding behaviour. In a more rigorous review of the HBM using stricter inclusion criteria than Janz and Becker (e.g. studies had to be published, encompass all four dimensions of the HBM, have assessed predictive validity), Harrison, Mullen, & Green (1992) found despite all components being significant predictors of behaviour, the effect sizes were small, with perceived susceptibility explaining at best 4% of the variance. However, from the perspective of public health, this could still be an important effect (Wardle, 2000).

The Theory of Reasoned Action (TRA; Fishbein & Ajzen, 1975) and the Theory of Planned Behavior (TPB: Ajzen, 1991), are frequently used to understand health behaviour (e.g. Armitage & Connor, 2001). Several authors have assumed that perceived risk is not fundamental to either of these two models (e.g. Hoogstraten, de Haan, & ter Horst, 1985; Ried & Christensen, 1988; Henning & Knowles, 1990; Steffen, 1990). However, in both

these models decisions about health behaviour are based on a subjective cost-benefit analysis in which the risk likelihood and the risk severity are conceived as major determinants of the attitudes construct towards health behaviours.

In both the HBM and PMT there are two measures of perceived threat: perceived vulnerability/susceptibility and perceived severity. The former refers to the likelihood or the probability of an event occurring while the latter refers to a person's evaluation of the health outcome. The focus of this thesis will be on judgements of likelihood and probability because the principal threat under consideration is cancer. Cancer is almost universally regarded as a serious and threatening condition (Champion, 1994; Curry & Emmons, 1994; Rimer, 1990), so the construct of perceived severity is less fruitful to explore. Furthermore, perceived severity has not been consistently associated with preventive behaviour in either of the meta-analyses (Janz & Becker, 1984; Harrison et al., 1992).

## 1.2. Are people accurate in their risk perceptions?

A feature of personal risk perception is that people tend to show consistent biases in their estimates. When making absolute risk judgements, people are inclined to underestimate large risks (e.g. diabetes) while overestimating small risks (e.g. plane crashes; Lichtenstein, Slovic, Fischhoff, Layman, & Combs, 1978; Slovic, 1987). Sutton (1999) reported the same effect in a large study of 20 years old in Britain, who were asked: *"On average, out of 1000 twenty-year-olds in Britain who smoke cigarettes regularly and who carry on smoking, how many do you think will be:*

*Murdered?*

*Killed on the roads?*

*Killed by smoking before age 70?"*

Sutton (1999) found that respondents accurately perceived that smoking would be the most likely cause of death, followed by road accidents, then murder. However, they greatly overestimated the likelihood of being killed on the road or murdered, while underestimating the risk of smoking. These results suggest that people may be relatively accurate in their risk perception, that is the orderings are similar to epidemiological findings and official statistics, but they tend to be biased in judging the magnitude of the risk. Other studies

have found that people's comparative estimates are ordinally accurate; nonsmokers give lower personal risk ratings for smoking-related illnesses than do smokers (McKenna, Warburton, & Winwood, 1993) and prostitutes give higher personal risk judgements for HIV (van der Velde, van der Plight, & Hooykaas, 1994).

### *1.2.1. Availability bias*[1]

One explanation for the phenomenon described by Lichtenstein et al. (1978) and Sutton (1999) is the availability bias (Tversky & Kahneman, 1974). This is the tendency for people to feel at greater risk of threats that can be easily brought to mind, either because of extensive media coverage or direct experience through having a family history or a close friend suffer from the threat. Greater 'availability of' a threat means that people may think about it more frequently and with greater clarity, leading them to feel the threat is more common and they are more vulnerable (Weinstein, 1987; 1989). Increased interest in bowel cancer screening in the US during the time when President Ronald Regan's bowel cancer scare received a great deal of media attention has been interpreted as a demonstration of the impact of the availability bias (Brown & Potosky, 1990). The availability bias has also been used to explain why women tend to overestimate the lethality of breast cancer compared with lung and colon cancers, arguing that breast cancer receives more media attention (Wilcox & Stefanick, 1999).

### *1.2.2. Biases at the individual level*

Another way to assess whether people are accurate in their risk perceptions in relation to predictable events is to compare subjective risk with objective risk. Assessing actual risk can be difficult and in studies obtaining an objective marker of risk there have been mixed results in terms of accuracy. A study measuring the relationship between subjective and objective risk of heart attack or stroke found that 43% of the 4171 participants were accurate in their estimation of risk, 40% underestimated their risk, and 18% overestimated their risk (Niknian, McKinlay, Rakowski, & Carleton, 1989) with similar results reported

[1] It is acknowledged that there are other heuristics influencing risk judgments such as the representativeness heuristic (Tversky & Kahneman, 1974), 'anchoring and adjustment' (Tversky & Kahneman, 1974), and the numerosity heuristic (Pelham, Sumarta, & Myaskovsky, 1994), however they are not of direct relevance to the current thesis and so are not discussed.

by Avis et al. (1989). Most work exploring the relationship between subjective and objective risk has been carried out within the context of breast cancer, possibly because of the relative ease of estimating objective risk using the Gail Model for breast cancer[2] (Gail et al., 1989). Several studies have found that women are very inaccurate in estimating their risk with between 80-98% of women in the studies overestimating their chances of developing breast cancer (Smith et al., 1996; Black, Nease, & Tosteson, 1995; Daly et al., 1996). One study (Skinner, Kreuter, Kobrin and Strecher, 1998) found that only 26% of women overestimated their risk of developing breast cancer, while 43% were accurate. The variability in accuracy seems to depend on how people are asked about their subjective risk. In the studies finding very high levels of overestimation, participants were asked to rate their perceived risk using an absolute measure (e.g. *"Rate your chance of getting breast cancer someday from 0-100%"*). The studies which found lower levels of overestimation (Niknian et al., 1989; Avis et al., 1989; Skinner et al, 1998) used a comparative risk measure (e.g. *"Compared with others of your same age and sex, how would you rate your chances of getting breast cancer?"* Response options: *lower than average/average/higher than average*). However, these results indicate that even using a comparative measure of perceived risk around 60% of people are inaccurate in estimating their risk.

### *1.2.3. Biases at the group level: Unrealistic optimism*

It is also possible to assess the accuracy of people's risk perceptions by examining biases at the group level. Using this approach it has been found that people tend to believe they are relatively invulnerable to a range of future threats relative to a group of similar others. Weinstein (1980) described this tendency as 'unrealistic optimism'. He developed the concept of unrealistic optimism in response to the observation that the majority of people report that their personal risk of a range of adverse events, including illnesses and accidents, is lower than average. While some individuals are very likely correct, as a group, this is logically not possible. As he says, "If all people claim their chances of experiencing a negative event are less than average, they are clearly making a systematic error, thus demonstrating unrealistic optimism" (Weinstein, 1980, p806). It is rare for "all

[2] The Gail model is based on five currently accepted risk factors for breast cancer: age; family history of breast cancer; age at first menstrual period; age at which a women gives birth to her first child; and the number of breast biopsies a women has had.

people" in the group to claim their risk is lower than average; many people will regard their risk as average, and some will believe they are at higher than average risk, but as a group, there tends to be an optimistic bias.

Typically, unrealistic optimism is assessed using the question described above (e.g. "*Compared with others of your same age and sex, how would you rate your chances of getting breast cancer?*", with response options of: *lower than average/average/higher than average,* usually scored -1, 0, +1 respectively). If the mean score of the sample for comparative perceived risk is significantly less than the midpoint (the score representing average risk i.e. 0), then this is evidence of an optimistic bias. Optimistic bias can also be measured indirectly by asking two questions (e.g. "*My chances of getting bowel cancer are:*" and "*Other people's chances of getting bowel cancer are:*" with the same response options in both cases: "*very unlikely/unlikely/moderate chance/likely/very likely*". The same individual would be asked both questions, or two groups of respondents may be used; one group giving their own risk judgement and the other estimating the risk of a target group (e.g. the average person of the same sex and age). The difference between the personal rating and the target group rating reflects the extent of the bias (Weinstein & Klein, 1996). Typically, personal risk judgements are lower than 'others' risk judgement.

Assessing bias at the group level, rather than at the individual level, has the advantage that objective markers of actual risk for each individual do not need to be calculated. However, within a group, an individual may perceive their risk as lower than average and be quite accurate in their estimation, they therefore should not be regarded as 'unrealistic'. Some authors therefore prefer to use the term 'comparative optimism' (Absetz, Aro, Rehnberg & Sutton, 2000) when describing group level biases, in recognition of the fact that those perceiving their risk to be lower than average may not all be 'unrealistic' in their estimation.

### 1.3. Unrealistic optimism/comparative optimism

Unrealistic optimism has been reported in over 300 empirical studies and has been described for a wide range of negative health events including: heart attack, food poisoning,

lung cancer, stroke, skin cancer, AIDS, drug addiction (e.g. Weinstein, 1984; Van der Velde et al., 1994). Unrealistic optimism is also sometimes referred to as 'optimistic bias'. Table 1.1 shows examples of unrealistic optimism described by Weinstein (1984; 1987). Each of the threats, with one exception, has a mean that deviates significantly below zero, therefore representing an optimistic bias. The one exception is cancer. Interestingly, an optimistic bias is seen for lung and skin cancer but not for cancer in general.

**Table 1.1: Mean comparative risk judgements (from Weinstein, 1984; 1987)**

| Threat | Rating | Significance |
|---|---|---|
| Alcoholism | -1.25 | $p<0.001$ |
| Tooth Decay | -0.71 | $p<0.001$ |
| Heart attack | -1.06 | $p<0.001$ |
| Chronic bronchitis or emphysema | -1.09 | $p<0.001$ |
| Gum disease | -0.77 | $p<0.001$ |
| Auto accident injury | -0.70 | $p<0.001$ |
| Diabetes | -0.65 | $p<0.01$ |
| Cancer | 0.09 | $p>0.01$ |
| Lung cancer | -0.77 | $p<0.001$ |
| Skin cancer | -0.77 | $p<0.001$ |

Comparative optimism is not only restricted to beliefs about the likelihood of experiencing negative events, but extends – in reverse - to positive events. People tend to believe that they are more likely than others to get a well paid job and to live past 80 years of age (Weinstein, 1980).

More rarely, groups of people show a 'pessimistic bias' – i.e. rate their risk of an adverse event as higher than average. Pessimistic biases tend to occur when people have direct experience of a threat such as a man-made or natural disaster. Dolinski, Gromski and Zawisza, (1987) found that Polish students who were exposed to intense radiation following the Chernobyl disaster reported unrealistic pessimism about suffering health problems as a result of their exposure, however they maintained their illusions of invulnerability in other areas of their lives.

### *1.3.1. Is comparative optimism the same as dispositional optimism?*

One might wonder if being relatively optimistic about a specific threat is a symptom of having a generic, optimistic disposition. Dispositional optimism refers to generalised outcome expectancies - a general belief that things will turn out well in life (Scheier & Carver, 1985). The two appear to be related constructs. Most studies have found a modest association between measures of dispositional optimism using the Life Orientation Test (LOT: Scheier & Carver, 1985) and specific optimistic beliefs ($r=0.27$, $p<0.05$, Davidson & Prkachin, 1997; $r=0.31$, $p<0.001$, Radcliffe & Klein, 2002). Armor and Taylor (1998) describe comparative optimism as "situated optimism" and suggest that (p.313), "knowledge of an individual's generalized expectancy will provide at best a partial estimate of how optimistic that individual will be for specific outcomes in specific situations". Therefore, although the effect is small, it does appear that there is some correspondence between dispositional optimism and comparative optimism.

### *1.3.2. Psychological explanations of optimistic bias*

Where does this optimistic bias come from? There are several possible psychological explanations for comparative optimism, with good overviews provided by Weinstein (1987), van der Pligt (1994; 1998) and Hoorens (1994).

*Cognitive explanations.* Cognitive biases and heuristics have been the focus of much of the work looking at the causes of erroneous risk judgments. One cognitive explanation for comparative optimism is what Weinstein (1980) termed 'egocentric bias'. This bias arises because people have more knowledge of their own protective behaviours than those of others (the availability bias, Tversky & Kahneman, 1974) and fail to recognise that the factors we perceive as lowering our own risk also lower our peers' risk (Ross & Sicoly, 1979; Weinstein, 1982). Perloff and Fetzer (1986) found that participants show perceived invulnerability for themselves, their closest friends and relatives, but not vague 'others' such as 'other students' or 'other friends'. It is possible that participants have greater knowledge of the health behaviours of those closest to them suggesting an extension of the egocentric bias. Weinstein (1983) found that when students described their own standing

on risk factors and were given explicit information about other students' standing on the same risk factors, optimistic biases were significantly reduced.

Another possible cognitive explanation relates to perceived control. People tend to have an exaggerated belief about their abilities in comparison to others (Alicke, 1985), and so insofar as threats are controllable, the optimistic bias will be more apparent. Some studies have found evidence in support of the role of control in optimistic biases (McKenna, 1993; Hoorens & Buunk, 1993), while others (Harris & Middleton, 1994; Lek & Bishop, 1995) concluded that there was no evidence that comparative optimism arises from the illusion that one has more control over illness vulnerability than others. However, in a meta-analysis Klein and Helweg-Larsen (2002) found a small but robust association between perceived control and optimistic bias suggesting that it makes a significant contribution to comparative optimism. The results of the meta-analysis therefore give weight to the argument that perceived control may be one of the key determinants of comparative optimism.

Personal experience may also contribute to comparative optimism because a lack of experience with a given threat makes it harder to imagine how it might affect us (an availability bias; Tversky & Kahneman, 1974). Thus, seeing close friends, relatives, or oneself experiencing the negative consequences of a threat tends to reduce optimistic beliefs about one's own personal risk.

Stereotypical beliefs may also be influential in comparative optimism. In thinking about others, people tend to compare themselves to a worse-case other who does nothing to reduce their risk rather than to 'the average person' as instructed (Weinstein, 1980). It seems that there is considerable overlap between stereotypical beliefs and egocentric bias as explanations, as they both rely on the participant having limited knowledge of the comparison target.

*Motivational explanations.* Motivational explanations focus on the need to reduce the fear associated with a threat, and rest on the assumption that the biases are deliberate distortions of a potentially known reality (Hoorens, 1994). The first process is defensive denial (Kirscht, Haefner, Kegeles, & Rosenstock, 1966); an attempt to avoid the anxiety one

would feel from admitting to a threat to wellbeing. If this were the case, more serious events would be expected to elicit more optimistic bias than would minor threats. The idea of defensive denial has, however, found little support as an explanation for comparative optimism (DeJoy, 1989; Weinstein, 1980; 1982; 1987) as seriousness of a threat is not correlated with the amount of optimistic bias.

A second possible motivational explanation is that individuals express optimistic views about their future risk as a means of enhancing or maintaining self-esteem. In estimating comparative risk, individuals typically think of peers with fewer positive attributes and at higher risk than themselves (Perloff & Fetzer, 1986) i.e. they make a downward social comparison and think of an unrealistic stereotype of a person who does nothing to improve his or her chances or even engages in counterproductive activity. Downward social comparisons can enhance self-esteem by making one feel good about one's situation relative to the comparison other (Taylor, Wood & Lichtman, 1983). Self-esteem maintenance is therefore related to the cognitive explanation of stereotypical beliefs as they both involve social comparison processes (van der Pligt, 1994). It is therefore difficult to conclude whether making a downward social comparison to less fortunate others represents a cognitive or a motivational explanation. Clearly people may be motivated to do this to protect their self-esteem but a cognitive bias must be involved for the majority of people to compare themselves with such an unfavourable target 'other'.

A third possibility could be that people believe 'hope' or optimistic statements are actually protective. Hope has been found to be health protective in the literature (Cousins, 1989; Gottschalk, 1985) and is a commonly expressed lay belief. People would therefore not wish to say their risk was above average for fear that expressing so might cause the adverse event to happen.

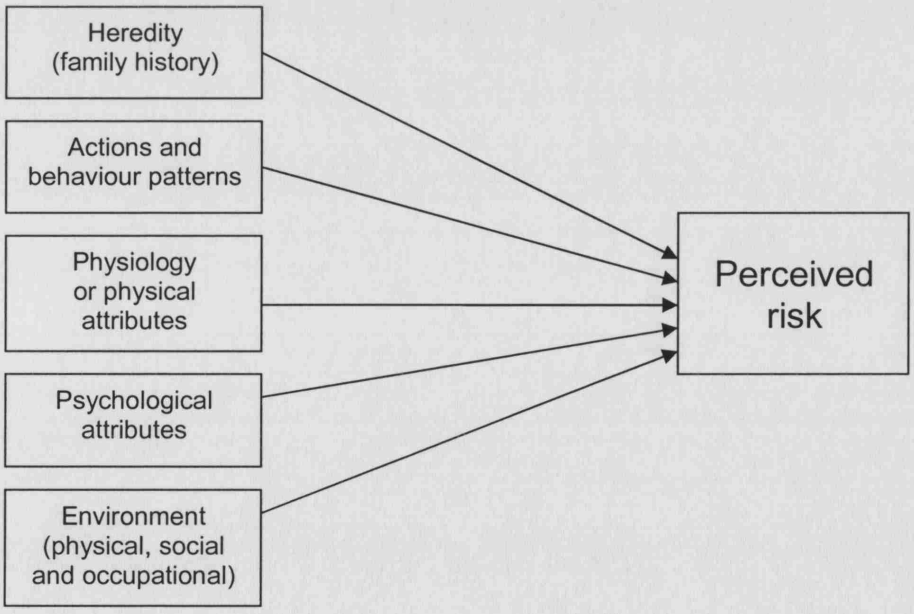
It seems that both cognitive and motivational factors influence comparative optimism and there is a certain amount of overlap between the different factors e.g. the availability heuristic and personal experience and ecocentric bias. Van der Pligt (1994) suggests that cognitive factors may be more influential in making absolute risk judgments while motivational factors are more relevant in explaining comparative risk judgments. Hoorens (1993) suggests that a useful way to think of the two explanations is to consider

motivational explanations as the 'why' of optimistic biases, while cognitive factors describe the 'how' of their emergence. However, considering that there is a degree of overlap between the two explanations, Hoorens' suggestion may be overly simplistic.

### *1.3.3. Lay people's explanations for their risk estimates*

*Weinstein's (1984) five factor framework.* Weinstein (1984) coded the reasons that individuals provided for their comparative risk judgements for a range of hazards (e.g. drug addiction, venereal disease, alcoholism, suicide, tooth decay etc.) into five categories. The five categories were: actions and behaviour patterns (maintain weight, brush teeth regularly, drink too much), heredity (family history of illness), physiology or physical attributes (for health problems, includes judgements of vulnerability based on past experience), psychological attributes (personality, values, likes and dislikes, and knowledge) and environmental factors (physical, social and occupational environments), see Figure 1.1.

**Figure 1.1: Weinstein's five factor framework of comparative perceived risk**




He found that the types of risk factors mentioned by participants varied significantly from risk to risk, however in general both personal actions and psychological attributes were

mentioned in an optimistically biased manner. That is, participants mentioned these factors as decreasing their risk, but rarely mentioned them as factors increasing their risk. Weinstein (1984) suggested that this was due to actions and psychological attributes being related to perceived control, and as noted in section 1.3.2. greater perceived control is associated with optimistic bias. Heredity and environmental attributes were viewed in a more balanced fashion with people acknowledging that their standing on these factors may increase or decrease their risk. Physiology or physical attributes were viewed in a more optimistically biased way and mentioned as risk decreasing factors.

In total, five studies were identified as using the Weinstein framework to 'code' people's reasons for their risk estimates. Two studies examined bowel cancer (Blalock, DeVellis, Afifi, & Sandler, 1990; Lipkus, Rimer, Lyna et al., 1996), two looked at breast cancer (Lipkus, Rimer, & Strigo, 1996; Aiken et al., 1995), and one study of 70 undergraduate students in Hong Kong considered a range of diseases e.g. AIDS, brain cancer, common cold, coronary heart disease etc. (Lek & Bishop, 1995). Table 1.2 describes examples of reasons which were coded within the five factors. Table 1.2 shows that there is modest consistency between studies in the types of items coded within the factors.

**Table 1.2: Examples of the five Weinstein factors**

| Author<br>*Threat* | Actions and behaviour patterns | Heredity | Physiology or physical attributes | Environment | Psychological attributes |
|---|---|---|---|---|---|
| Weinstein (1984)<br>*Variety of health and safety risks* | "I try to stay in shape." "I drink too much." "I would get help if I ever got that depressed." "I brush my teeth regularly." "I travel in a group at night." | "My father has diabetes." "Heart failure is rare in my family." | "I haven't had any cavities so far." "I get lots of colds." " I have low blood pressure." "I'm small and look like a good target for a mugger." "I don't like the taste of alcohol." | "There's a lot of pollution where I come from." "I don't plan to be in a high stress occupation." "My roommates all smoke a lot." "My friends are good drivers." "My job is in a high crime area." | "I don't believe in suicide." "I enjoy driving." "I know too many people with drinking problems to let that happen to me." "I don't let problems get to me." "I'm very health minded." |
| Blalock, Devellis, Afifi, & Sandler (1990)<br>*Bowel cancer* | (Poor) diet.<br>Try to eat properly | So much cancer in the family<br>All family in real good health | Has burning in stomach<br>Never had any problems | All the things they put in food<br>Never had a job requiring strenuous work | Feel like I could get it<br>Trust that I won't get it |
| Lipkus, Rimer, Lyna et al., (1996)<br>*Bowel cancer* | Diet, exercise, smoking | Family history | Stomach burning | All the things they put into food | Feel that I could get it. |
| Aiken, Fenaughty, West, Johnson, & Luckett (1995)<br>*Breast cancer* | Diet (high fat); medication (took estrogen)<br>Diet (low fat, no fried food, low red meat); medication (took vitamin C, did not take birth control pills); exercise; infrequent alcohol; get mammograms | Family history of breast cancer<br>No family history of breast cancer; lucky ancestors; family has other disease | Fibrocystic breast disease; breast lumps; no children; children born at late age<br>No cysts, growths or fibrocystic tissue; children born at early age; small breasts; breast feeding; overall good health; having been pregnant | Pesticides; preservatives<br>Job does not expose to radiation; smoke-free house | Under stress<br>Not a cancer personality; does not think about or dwell on breast cancer; being indestructible |
| Lipkus, Rimer, & Strigo (1996)<br>*Breast cancer* | Diet, exercise, smoking | Family history | Medical history, breast feeding, having children, age | Pesticides | Stress, personality, feeling hopeful |
| Lek & Bishop (1995)<br>*Variety of health and safety risks* | "I drink too much." "I stay in shape by exercising." | "Heart disease runs in my family." "My father had lung cancer." | "I get lots of cold." "I've always been healthy." | "My friends around me smoke a lot." "My environment is pollution free." | "I don't believe in getting lung disease." "I'm a very tense and stressed person." |

## 1.4. The consequences of comparative optimism

The major concern with comparative optimism is that because people feel at lower than average risk (possibly to an unrealistic degree) they may be less likely to take steps to protect their health. If a person believes that they are much less likely than similar others to develop a condition, it is understandable that they may not be motivated to engage in health-protective behaviours.

As mentioned earlier, feeling at increased risk of disease or illness has been associated with a range of health behaviours. In the screening literature, higher perceived risk is associated with intention to take a bowel screening test (Myers, Vernon, Tilley, Lu, & Watts, 1998), prostate screening (Taylor et al., 1999), mammography screening (Katapodi, Lee, Facione, & Dodd, 2004), and cervical screening (Kahn, Goodman, Slap, Huang, & Emmons, 2001). Many studies go further in showing a level of 'dose-response' in the relationship between perceived susceptibility and utilization of protective behaviours such as cancer screening (Myers et al., 1998; Wardle et al., 2000; Codori, Petersen, Miglioretti, & Boyd, 2001).

While this line of reasoning has intuitive appeal, and the studies reviewed suggest a relationship between perceived risk and behaviour, the relationship has not always been clear. A meta-analysis of the relationship between perceived risk for breast cancer and mammography screening found that in 18 out of the 19 studies reviewed, perceived risk was positively associated with mammography screening (McCaul et al, 1996), but the average effect size was only r=0.16. In a meta-analysis of the HBM (Harrison et al., 1992), which restricted the analysis to studies meeting their strict criteria, the same relationship between perceived susceptibility and behaviour emerged (r=0.15). In a review of the relationship between perceived risk and participation in faecal occult blood testing, Vernon (1997) found that two of eight studies reported a positive association (Farrands, Hardcastle, Chamberlain, & Moss, 1984; Price, 1993), while six studies found no relationship (Halper, Winawer, Brody, Andrews, Roth, & Burton, 1980; Macrae, Hill, St John, Ambikapathy, & Garner, 1984; Burack & Liang, 1987; Sandler, DeVellis, Blalock, & Holland, 1989; Hoogewerf, Hislop, Morrison, Burns, & Sizto, 1990; Myers et al., 1994). Three studies examining the association between perceived risk and flexible sigmoidoscopy (FS)

screening have found a positive relationship (Kelly & Shank, 1992; Lewis & Jensen, 1996; Wardle et al., 2000).

*Interpreting the relationship between perceived risk and behaviour.* Findings such as these call into question the pivotal role of perceived risk in health behaviour (Leventhal, Kelly, & Leventhal, 1999). Weinstein and Nicolich (1993) were the first to highlight that the uncertain relationship between perceived risk and behaviour may be the result of inappropriate measurement and interpretation of the relationship. One difficulty with cross-sectional studies is the interpretation of the association e.g. X believes they are at risk of developing bowel cancer and therefore decides to have a FS screening test. In this case high perceived risk leads to safer behaviour (the motivational hypothesis, see Figure 1.2). However having had the FS bowel screen and been given the all clear, X may now estimate his risk of developing bowel cancer as low (the accuracy hypothesis, see Figure 1.3). Cross-sectional data are therefore problematic as one cannot determine whether beliefs give rise to behaviour or vice versa. Because in the past some studies have not controlled for prior behaviour, they may have thought they were testing the motivational hypothesis but in actual fact been testing the accuracy hypothesis. Weinstein and Nicolich conclude that these errors may well explain the inconsistent and weak relationship between perceived risk and behaviour that has been reported by some studies.

**Figure 1.2: The Motivational Hypothesis**

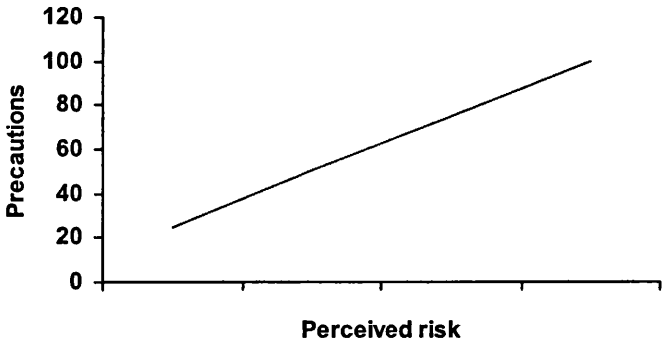
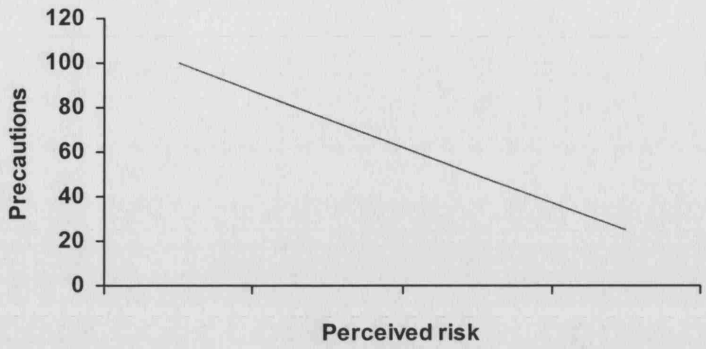


**Figure 1.3: The Accuracy Hypothesis**

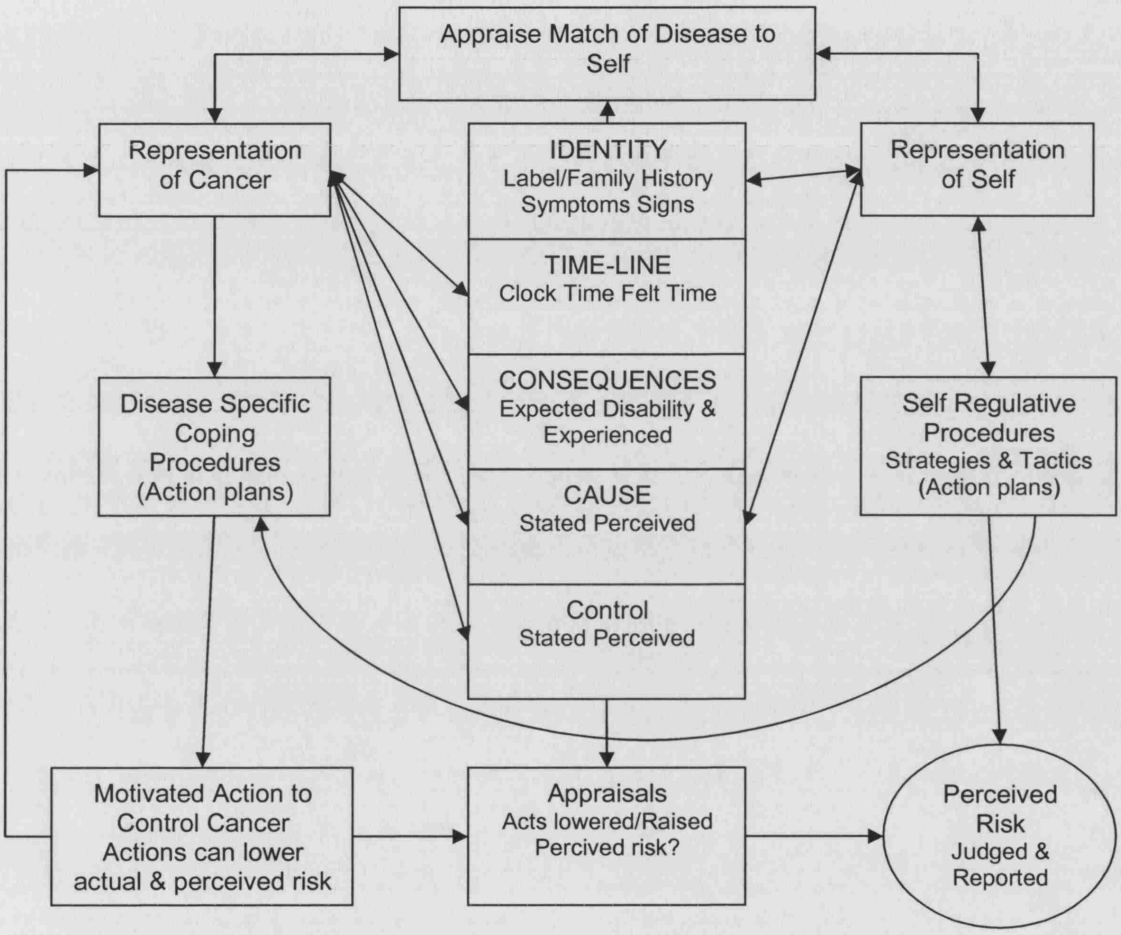



In their meta-analysis, Harrison et al. (1992) calculated effect sizes for different types of study design including prospective studies. We should therefore be fairly confident in the case of prospective studies that the motivational hypothesis is being appropriately tested. And although even prospective studies showed the relationship between perceived risk and behaviour to be small r=0.19, small effects have important explanatory value at a population level (Wardle, 2000).

*A framework for understanding the relationship between perceived risk and behaviour.* Leventhal et al. (1999) presented a self-regulatory framework for understanding illness threats as part of a Journal of the National Cancer Institute Monograph on risk perception, see Figure 1.4. The aim was to explain the weak relationship between perceived risk and behaviour. It was built around the five 'common sense' domains of illness (identity, time line, consequences, cause, and control; Leventhal et al., 1992; Weinman et al., 1996). It proposes that, "the overlap between the factors defining the representation of cancer and those defining the representation of the self establishes the self-relevance of the disease." Leventhal et al. go on to explain that: "correspondence between perceived risk and motivated action to control cancer will increase with greater overlap between factors involved in the representation of cancer and the self, and this increase can result in a more congenial relationship between general, self-regulative procedures and medical recommendations for cancer control." It is not clear how this model could be easily operationalised and tested which makes it difficult to further our understanding of perceived risk. For example, it is not clear how one would measure the representation of the self or the representation of cancer, indeed we know that with bowel cancer people have

very little knowledge of the disease (McCaffery, Wardle, & Waller, 2003) making it difficult to imagine how one might operationalise 'representation of bowel cancer'.

**Figure 1.4: Leventhal, Kelly & Leventhal's (1999) framework of illness threat**




## 1.5. Can optimistic bias be reduced?

This review of the comparative optimism literature has shown that optimistic beliefs about the chances of developing various types of disease are common and are associated – albeit weakly with health behaviours. Taken together, these findings suggest that optimistic bias has important implications for public health. This points to the value of developing strategies to reduce overly optimistic beliefs so people are more motivated to protect their health.

Whenever there is an important gap between what people believe and the prevailing scientific account, there is an opportunity for health-education to intervene. Long ago it was proposed that challenging the belief that one is personally exempt from a threat (Hovland, Janis & Kelley, 1953), in those who are most likely to display optimistic beliefs will have the effect of reducing optimistic bias. Stapel and Velthuijsen (1996) found that giving people newspaper reports which were more self-relevant (the victim described in the newspaper report having the same occupation as the reader), increased personal risk judgements.

Disabusing people of unrealistic optimism could save lives if, as a result of feeling less invulnerable to a disease or illness, these new 'realists' participated in health protective behaviours. The downside is that optimism, unrealistic or otherwise, might be psychologically protective (Taylor & Brown, 1988). However, most contemporary health educators probably take the view that people should be aware of, and indeed accurate about, their health risks if there are health benefits that could follow from this awareness. Were a person to develop bowel cancer, after having turned down screening on the basis that they were not at risk, they might reasonably wish that someone had told them that their previous risk assessment was wrong.

Attempts to modify people's sense of risk ('debiasing' as it is sometimes called) have had mixed success. A few studies have successfully increased perceptions of risk. In one study, homeowner's perceptions of risk for their own homes having unhealthy radon levels were significantly increased by informing them that there was a "substantial probability" of finding high radon levels in homes in their neighbourhood (Weinstein, Sandman, & Roberts, 1990; Sandman & Weinstein, 1993). Another study reported that asking young women to review the number of times they had had unprotected sex increased perceptions of risk for contracting a sexually transmitted disease or having an unplanned pregnancy (Gerrard, Gibbons & Warner, 1991; Smith, Gerrard, & Gibbons, 1997; Boney-McCoy, Gibbons, & Gerrard, 1999). In a sample of students, Weinstein (1983) found that when the students described their standing on health and safety risks (e.g. heart attack, diabetes, drinking problem, lung cancer) and were given information about the risk status of their peers, the optimistic bias was reduced. However, if the students only rated their standing

on risk factors without receiving information on the risk status of peers, optimistic beliefs were increased. The results therefore suggest that information about peers reduces unrealistic beliefs, but merely rating oneself on risk factors substantially increases optimistic biases.

However, other attempts have been less successful (Griffeth & Rogers, 1976; Sutton & Eiser, 1990). In a series of experiments, Weinstein and Klein (1995) failed to eliminate the optimism bias, and found that providing a list of risk factors and asking participants to think of a high-risk image served counter-intuitively to increase optimistic beliefs about developing heart disease, alcoholism or a weight problem. A limitation of these studies is that they were predominantly based on student samples with one exception[3] and the sample sizes were comparatively small (ranging from 164 to 374). It is possible that students may react differently to risk information than the general population because they are younger and possibly feel more invulnerable. A difference in perceived risk between an intervention and a control group is a small effect which requires a large sample to detect it. In the studies by Weinstein and Klein (1995) there were approximately N=100 participants per group. They did not report a power calculation and so it is possible that these sample sizes were not sufficiently powered to detect a subtle difference between groups. A further limitation was that Weinstein and Klein were addressing familiar health problems (e.g. heart disease, alcoholism, weight problem) and so participants may have had a certain level of knowledge of the risk factors. It is possible that informing people about risks they have little knowledge of may have a greater impact on risk perceptions, which could explain why the intervention on home radon levels was successful (Weinstein, Sandman, & Roberts, 1990; Sandman & Weinstein, 1993). Weinstein and Klein (1995) conclude that providing information about unfamiliar hazards and providing information about the standing of peers on important risk factors appear more likely to reduce optimistic biases.

This chapter has reviewed the biases in risk perception, particularly comparative optimism. Psychological and lay people's explanations for risk estimates have also been discussed. Consideration has also been given to the relationship between perceived risk and behaviour

[3] Study 1 was based on a non-student survey of New Jersey residents with a median age of 39 years.

and whether it is possible to change perceptions of risk. The next chapter describes perceptions of risk in the cancer literature.

# CHAPTER 2

## Perceptions of cancer risk

### 2.1. Perceived risk and comparative optimism in the cancer literature

The early studies of unrealistic optimism tended to measure the phenomenon over a number of health and safety threats. However, Weinstein (1987) suggested that the study of the origins of risk perceptions would benefit from more thorough investigation of specific hazards. The focus of this thesis is therefore on how people perceive their risk for the specific threat of bowel cancer. This is particularly relevant because the Secretary of State for Health has announced that nationwide bowel screening will be introduced in the UK by April 2006. If a screening programme is to be effective, then as many of the population as possible need to be sufficiently motivated to participate. If invulnerability beliefs are widespread, this could limit the potential benefits of the new screening programme.

Most work on risk perception in the cancer literature has concentrated on breast cancer (e.g. Aiken et al., 1995; Lipkus, Rimer, & Strigo, 1996; Woloshin, Schwartz, Black, & Welch, 1999). Relatively few studies have addressed perceptions of risk for bowel cancer, making it an area ripe for investigation. Because of the small number of studies looking specifically at bowel cancer, the literature on perceptions of risk for all types of cancer was reviewed.

Comparative optimism has been demonstrated for a range of cancers including breast, colon and lung cancer. The percentage of respondents perceiving themselves to be at lower risk of breast cancer than others ranges from 22% to almost 50% (Aiken et al., 1995; Lipkus, Rimer, & Strigo, 1996; Woloshin et al., 1999) compared with between 10 and 17% who perceive themselves to be at higher risk. Similarly, in a study examining risk perceptions of the chance of developing oral cancer (a smoking-related disease) more than

one in four smokers identified their risk as less than others[4] of their age and sex (Hay et al., 2002). Even more extreme results have been reported for bowel cancer; 36% of a sample of 547 predominantly low-income African Americans estimated their bowel cancer risk to be below average, while only 4% believed they were at above average risk (Lipkus, Rimer, Lyna et al., 1996). And among 124 first degree relatives (FDRs) of patients with bowel cancer who had been explicitly informed of their increased risk status in a letter, 29% still described themselves to be at lower risk than others of the same age (Blalock et al., 1990).

Only one study was identified as looking at perceptions of cancer risk in a population sample in the UK. Grunfeld, Ramirez, Hunter and Richards (2002) reported that 17% of the 1830 women interviewed saw their risk as lower than average, while only 7% perceived themselves to be at higher than average risk, suggesting an optimistic bias in the sample as a whole, but only a minority deviating from 'average risk'.

These studies indicate that people are optimistically biased when estimating their risk of developing various types of cancer. However, in reviewing the literature it was evident that no studies had considered perceptions of bowel cancer risk in a population sample or in a country other than the US.

## 2.2. Are certain subgroups more comparatively optimistic?

Identifying population subgroups who are most optimistic or studying the psychological characteristics of comparative optimists versus pessimists has been an under-researched area (Vernon, 1999). Montgomery, Erblich, Dilorenzo, & Bovbjerg (2003) commented: "Outside breast cancer research, the literature on the predictors of perceived risk of disease is far less developed." Interventions designed to enhance health behaviours might also benefit from a clearer understanding of the correlates of risk perception, in order that risk communications can be targeted at the most vulnerable population subgroups and possible misperceptions addressed.

[4] 27% of smokers saw their risk of developing oral cancer as less than unspecified others of the same sex and age. 31% of smokers saw their risk as lower than that of other smokers, and 19% of smokers saw their risk as lower than non-smokers.

*2.2.1. Demographic factors and perceived risk*

Age is one demographic factor which has been investigated more than others. Perceived risk of breast cancer has been shown to decrease with age (Vernon, Vogel, Halabi, & Bondy, 1993; Grunfeld et al., 2002) and similarly perceptions of bowel cancer risk were lower in the oldest age group (Price, 1993; Vernon, Myers, Tilley & Li, 2001). Other studies have found no relationship between age and perceived risk for developing cancer (Lipkus, Rimer, Lyna et al., 1996; Skinner et al., 1998; Erblich et al., 2000). However, in a meta-analysis of perceptions of breast cancer risk, Katapodi et al. (2004) reported that 7/12 studies found younger women feel more at risk. To highlight the problem, in reviewing the literature, I did not find a single study reporting that older adults, who are more objectively at risk, felt less optimistic.

Gender has not been much studied in relation to perceived risk for cancer because the majority of research has focused on risk for breast cancer. But where gender differences have been studied, results have been inconsistent. Price (1993) found women to be more optimistic than men about their chances of developing bowel cancer, while Lipkus, Rimer, Lyna et al. (1996) and Wardle et al. (2000) found no gender difference. Kreuter and Strecher (1995) found women to be less optimistic than men for risk of developing cancer in general. Thus, the relationship between gender and perceived risk remains unclear and warrants further investigation.

A few studies of ethnicity and perceived risk have been carried out in the United States. Uptake of cancer-preventive behaviours such as screening is lower among non-white groups (Blanchard et al., 2004), which could be because they feel less vulnerable and therefore less motivated to take steps to protect their health. Indeed studies have found that African Americans and those classified as 'non-white' are more optimistic than whites both for perceived risk of breast cancer (Skinner et al., 1998; Katapodi et al., 2004) and bowel cancer (Vernon et al., 2001). However, the association between ethnicity and perceived risk has not been explored in population samples, nor at all in the UK.

Many studies in the risk perception literature have included socioeconomic status (SES) indicators such as education and income, but associations with perceived risk have been

inconsistent. Some studies have found no association (Price, 1993; Vernon et al., 1993; Erblich, et al., 2000). Kreuter and Strecher (1995) found people with fewer years of education to be more optimistic about their chances of developing cancer, while Skinner et al. (1998) found that both the highest and lowest education groups were more optimistic about their chance of developing breast cancer than the middle education group. People in more prestigious jobs have been found to be more optimistic about their chances of developing cancer (Weinstein, 1987). The same pattern was reported in a UK based study where women in professional and intermediate occupations were significantly more optimistic about their chances of developing breast cancer than women in partly skilled and unskilled occupations (Grunfeld et al., 2002). This is the opposite of the true risk patterning where higher SES women are at greater risk (Quinn, Babb, Brock, Kirby, & Jones, 2001). A study carried out in Scotland also found a trend for more affluent participants (assessed using an individual deprivation measure) to be more optimistic about their risk of developing bowel cancer, but the result was not significant (Wardle, McCaffery, Nadel, & Atkin, 2004). The true relationship is therefore somewhat unclear.

It is difficult to generalise from these findings. The studies described used a variety of population subgroups: women (Vernon et al., 1993; Skinner et al., 1998; Erblich et al., 2000; Grunfeld et al., 2002) male automotive workers (Vernon et al., 2001); low SES groups (Price, 1993); and predominantly low income African Americans (Lipkus, Rimer, Lyna et al., 1996). They also used different measures including: comparative risk (Kreuter & Strecher, 1995; Lipkus, Rimer, Lyna et al., 1996; Skinner et al., 1998; Grunfeld et al., 2002); comparative risk with an unusual scoring system (Price, 1993); absolute numeric risk (Erblich et al., 2000); and absolute verbal risk (Vernon et al., 1993; Vernon et al., 2001). But even accounting for these differences, the relationship between the various demographic factors and perceived risk was not apparent. The most compelling evidence came from the meta-analysis (Katapodi et al., 2004) and the study by Grunfeld et al. (2002) based on a population sample. Both studies reported that comparatively optimistic beliefs were more prevalent in older age groups. Katapodi et al. (2004) found that non-white women were more optimistic but Grunfeld et al., (2002) did not report the relationship between perceived risk and ethnicity. However, even within these two more 'reliable' studies differences emerged in terms of SES. Grunfeld et al. found women with professional and intermediate occupations (possibly indicating higher educational

achievement) were more optimistic, while Katapodi et al. concluded that women with college education were less likely to have an optimistic bias. Further, both studies were based on perceptions of risk for breast cancer and so are limited to women. The only population sample including both men and women found no effect of gender on perceptions of risk for bowel cancer (Wardle et al., 2000).

### *2.2.2. Health related factors and perceived risk*

A family history of the disease is one of the few factors that is consistently linked to higher perceived risk (Blalock et al, 1990; Vernon et al., 1993; Aiken et al., 1995; Lipkus, Rimer, & Strigo, 1996; Erblich et al., 2000). Having a family history was the single most important factor identified by older adults as determining their perceived risk for bowel cancer in a qualitative study in the US (Weitzman, Zapka, Estabrook, & Goins, 2001). Male automotive employees with a family history of bowel cancer or polyps (small growths in the bowel wall) perceived their risk of bowel cancer to be significantly higher than those without a family history (Vernon et al., 2001). One explanation is that personal experience with the illness provides the opportunity to feel vulnerable through a process of vicarious learning (Weinstein, 1987; 1989; Schwarzer, 1994). Another is that people may believe they are genetically predisposed if a close relative has had the illness. Qualitative data tend to support the genetic explanation with heredity being mentioned as a risk-increasing factor for bowel cancer in those with a family history of bowel cancer (Blalock et al., 1990), and in a sample of lower-income African Americans (Lipkus, Rimer, Lyna et al., 1996). It has also been viewed as a risk-increasing factor for cancer in general (Helzlsouer, Ford, Hayward, Midzenski, & Perry, 1994; Honda & Neuget, 2004).

Poorer subjective health has been related to higher risk perceptions (Helzlsouer et al., 1994), though this could be due to confounding, since poorer health is related both to lower SES, more likelihood of visits to doctors, and higher levels of anxiety and depression. More specific health factors have also been linked with perceptions of risk in the area of breast cancer, where a meta-analysis by Katapodi et al. (2004) found that self-reported breast problems were associated with increased perceived risk for breast cancer.

Health behaviours are often found to be associated with perceived risk for cancer, whether or not there is a specific epidemiological link. In general, individuals with healthier behaviour patterns perceive their risk to be lower than their peers, e.g. non-smokers (correctly) perceive their overall risk of developing cancer as lower than smokers (Vernon et al., 1993; Helzlsouer et al., 1994; Lipkus, Rimer, Lyna et al., 1996; Skinner et al., 1998; Vernon et al., 2001). Lipkus, Rimer and Strigo (1996) also found that participants in their telephone survey of older women viewed exercise, diet and not smoking as risk-decreasing factors for breast cancer. The association between health behaviours and comparative optimism may be partly explained by perceived control and the belief that one is able to take active steps to protect one's health.

### *2.2.3. Psychological factors and perceived risk*

Emotional factors have been shown to be associated with risk perceptions in many studies (e.g. Slovic, 1999). People with high levels of state anxiety generally display less of an optimistic bias than non-anxious people (Dewberry, Ing, James, Nixon, & Richards, 1990; MacLeod, Williams, & Berekian, 1991). A study of African-American women's risk perceptions for breast cancer showed that those who overestimated their risk of developing breast cancer had higher scores on depression and anxiety (Bowen, Hickman, & Powers, 1997).

### *2.2.4. Conclusions about the correlates of perceived risk*

In reviewing the literature on the correlates of perceived risk for cancer, I identified only four studies investigating the correlates of perceived risk for bowel cancer (Blalock et al, 1990; Price, 1993; Lipkus, Rimer & Lyna, 1996; Vernon et al., 2001). None used a population-based sample focusing instead on specific population subgroups; siblings of bowel cancer patients (Blalock et al., 1990), African Americans (Lipkus, Rimer & Lyna, 1996), low income men and women (Price, 1993), and white, male, automotive industry workers (Vernon et al., 2001). Further, no previous study has included a broad range of demographic, health and psychological factors in a multivariate model.

## 2.3. Is comparative optimism warranted? Relationship between perceived risk and clinical endpoints

Given that the social cognition models predict that people who are comparatively optimistic about their cancer risk are less likely to take steps to reduce their risk, it seems important to discover if people are in any way correct in perceiving their risk to be lower. Optimism in general (dispositional optimism) is associated with better self-reported health, better physician rated health, fewer visits to the doctor, increased survival time following a heart attack, greater immunological efficiency, successful completion of rehabilitation programs and longevity (Peterson & Bossio, 2001). Indeed, Allison, Guichard, Fung and Gilain, (2003) found that after controlling for known predictors of head and neck cancer survival, optimists were more likely than pessimists to be alive at 1 year.

One explanation of why optimists do better is that they tend to be more attentive to relevant health information, even if it is threatening (Aspinwall & Brunhart, 1996). It is possible that this increased vigilance to health information might help offset their risk of an adverse condition before it develops. Dispositional optimism and specific optimistic beliefs have been found to be related (Davidson & Prkachin, 1997; Radcliffe & Klein, 2002) and so specific optimism about cancer risk may not be entirely unrealistic.

Comparing subjective risk with objective risk has the advantage of detecting optimistic bias at the individual level, unlike most studies of comparative optimism which can only assess optimistic bias at the group level. Most attempts to assess the accuracy of risk judgements have compared personal risk appraisals with results from risk algorithms such as the Gail Model for breast cancer (Gail et al., 1989). Lipkus, Rimer and Strigo (1996) found a small ($r=0.21$) but significant relationship between comparative risk of developing breast cancer and Gail Model score in a survey of 364 women aged over 50 years who had received two or fewer mammograms in a 36 month period. A similar association was found between perceived risk and actual risk (based on the Gail Model and age-specific population-based rates of breast cancer death) in a random sample of 201 female veterans (Woloshin et al., 1999). A recent study of bowel cancer in 343 male and female members of a HMO also used a risk algorithm (the Harvard Colon Cancer Risk Assessment and Communication Tool for Research; Colditz et al., 2000) and found an association of $r=0.22$ ($p<0.0001$)

between perceived comparative risk and actual risk of bowel cancer (Weinstein et al., 2004). Kreuter and Strecher (1995) used health risk appraisal algorithms to assess risks of developing heart disease, stroke, cancer, or having a motor vehicle crash, in 1317 men and women from a sample of eight family medicine practices. In all cases comparative optimists were more likely to be in the actuarially lower risk category and comparative pessimists in the actuarially higher risk category.

These results would appear to indicate that there may be some validity to optimistic risk estimates. However, interpretation of these results must be tempered by the modest accuracy of risk algorithms in assessing 'true risk'. The ideal data would be true clinical outcomes, but only one study in the literature, which addressed perceptions of risk for cardio-vascular disease (CVD), has reported a clinical endpoint. This study found evidence that risk perception was strongly related to CVD morbidity and mortality over 10 years (McKenney et al., 1995). To the best of my knowledge, no study using clinical outcome has been reported in the cancer field.

Dispositional optimism has been consistently associated with favourable health outcomes (Peterson & Bossio, 2001). However, the literature on the relationship between optimism for specific threats and health outcomes is not conclusive. In section 1.3.1, it was argued that there may be some overlap between dispositional optimism and 'situated optimism' (Armor & Taylor, 1998), suggesting that exploring the relationship between comparative optimism for a specific threat and health may be valuable.

## 2.4. Lay people's explanations for their cancer risk estimates

### *2.4.1. Weinstein's (1984) five factor framework*

Weinstein's (1984) five factor framework (heredity, actions and behaviour patterns, physiology, psychological attributes, environmental factors) has been used to explore lay people's explanations for their cancer judgements in 4 studies. In two breast cancer studies, the most frequently mentioned reason for risk judgments was heredity. Physiology was the second most mentioned followed by personal actions in one study (Lipkus, Rimer, & Strigo, 1996), while personal actions were second most cited followed by physiology in the

other (Aiken et al., 1995). Psychological factors such as stress and feeling hopeful were less frequently mentioned and environmental factors were seldom mentioned in either study.

Blalock et al. (1990) examined the explanations given for comparative bowel cancer risk judgments in two groups: 1) 'high risk group' - FDR of someone with bowel cancer (n=124); 2) 'average risk group' FDR of someone having a surgery (n=171). Among the high risk group, 27% gave physiology as a reason, 25% heredity and 16% mentioned personal actions. In the average risk group, 27% cited personal actions, 27% mentioned physiology and 10% reported heredity in explaining their risk estimate. Environmental and psychological factors were mentioned infrequently in either group. It was somewhat surprising that even amongst the FDR of someone with bowel cancer who had been explicitly informed that they were at increased risk, only 25% gave heredity as an explanation. In contrast, in Lipkus, Rimer, Lyna et al.'s (1996) study of predominantly low income African Americans, psychological factors were the most frequently cited reason (22%), followed by heredity (12%), personal actions (10%), physiology (7%) and again, environmental factors were mentioned rarely (0.005%). It is unclear why psychological factors were so frequently mentioned in this sample compared to the other studies, but it suggests that older African Americans may be more likely to explain cancer in terms of psychological causes.

In considering lay people's explanations for risk estimates, existing studies have typically used one of two designs. They have either asked respondents the reason for their judgement in an open-ended fashion or they have related the level of optimism/perceived risk to one or two of the factors. Several studies (Blalock et al., 1990; Aiken et al., 1995; Lek & Bishop, 1995; Lipkus, Rimer, Lyna et al, 1996; Lipkus, Rimer, & Strigo, 1996) using the former approach have evaluated Weinstein's scheme by coding responses into one of the five categories. Studies using the second approach have either looked at each predictor variable in isolation (e.g. Hay et al., 2002) or have only assessed one or two of the five factors in multivariate analyses (Helzlsouer et al., 1994; Vernon et al., 2001). Weinstein's (1984) five factors provide a useful framework for understanding the determinants of perceived risk, and there is some evidence of its value in understanding perceptions of cancer risk (Blalock et al., 1990; Aiken et al., 1995; Lipkus, Rimer, &

Strigo, 1996). However, no study, to my knowledge, has assessed the extent to which the five factors in combination 'explain' the variation in perceived risk. This seems a crucial question to be answered if we are to understand fully the determinants of perceived risk.

### *2.4.2. The five 'common sense' domains of illness*

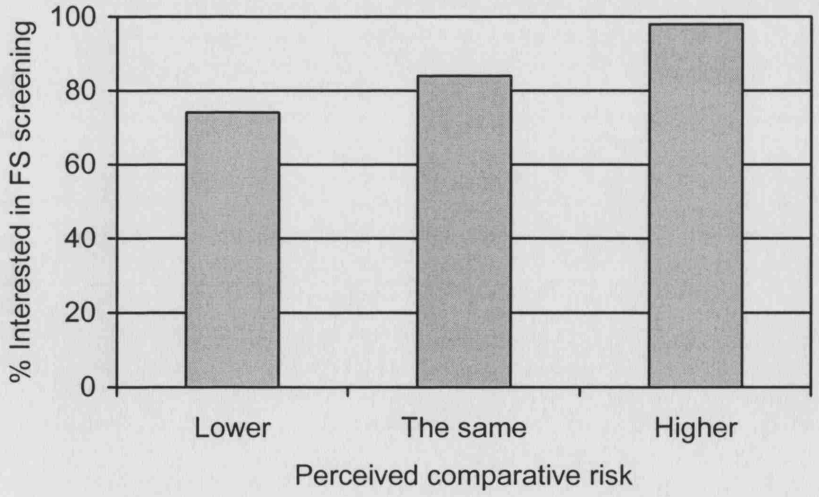
One recent study used the five domains characteristic of the Common Sense Model (identity, time line, consequences, cause, and control; Leventhal et al., 1992; Weinman et al., 1996) to examine reasons for risk estimates in individuals at risk for BRCA1/2 mutations (Kelly et al., 2005). Explanations given by the 99 Ashhenazi Jewish participants, both before and after gene testing, were coded into the five attributes of the common sense model: 1) causes of cancer (e.g. family history, mutation status); 2) control or cure of cancer through health behaviours and/or surgery; and 3) perceived timeline for developing cancer (e.g. time left in life to develop cancer); 4) label or identity (statistics and luck). Consequences were not given as a reason. Interestingly, people did not mention risk estimates given in counselling as reasons for their risk judgements post genetic testing, and so on the whole reasons given did not vary greatly between pre and post testing. This is surprising, and the authors provide three explanations for this unexpected result: 1) risk estimates given in counselling were implicit in their responses, 2) participants may not have given attention to risk information presented in counselling, or 3) probability does not weigh heavily in the perception of risk. Two reasons were given by participants which were not consistent with domains of the common sense model, these were: being Ashkenazi Jewish and optimistic. It seems that using the five attributes of the common sense model fails to capture the broad range of explanations that the Weinstein (1984) five factor framework can incorporate. For example, the two items (being Ashkenazi Jewish and optimistic) would seem to fit under the psychological attributes factor of the Weinstein framework. The examples given by Kelly et al. (2005) might be readily recoded into the five Weinstein factors: 'causes' (family history, mutation status) may be classified as 'heredity' or 'physiology'; 'control or cure' (health behaviours or surgery) under 'actions or behaviour patterns'; and 'timeline' (time left in life to develop cancer) coded as 'physiology'. The only additional benefit of the five attributes of the common sense model

is the 'label or identity' (statistics and luck) factor which is not fully captured by Weinstein's (1984) framework, although luck could be thought of as a psychological factor.

## 2.5. Perceived risk and bowel screening

The context of the UK FS Trial provided a unique opportunity to appropriately test the relationship between perceived risk for developing bowel cancer and interest in screening because none of the participants had been screened for bowel cancer in the past as screening is not otherwise available in the UK, and those who had recently had their bowel examined for diagnostic purposes were excluded from the Trial (UK Flexible Sigmoidoscopy Screening Trial Investigators, 2002). Therefore risk judgements were not confounded by prior screening behaviour. Data from the UK FS Trial pilot centres found that 98% of those who perceived their risk of developing bowel cancer as higher than others were interested in FS screening compared with 84% who viewed their risk as 'the same' and 74% who perceived their risk to be lower than average (see Figure 2.1; Wardle et al., 2000). This suggests that, as the social cognition models predict, perceived risk is an important determinant of screening behaviour. This meant that in focusing on perceptions of risk for bowel cancer, this thesis could have practical implications.

**Figure 2.1: 'Dose-response' relationship between perceived risk of developing bowel cancer and interest in screening (Wardle et al., 2000)**



It was not possible to assess the relationship between perceived risk and screening attendance in the UK FS Trial due to the two-stage recruitment process. Only participants who indicated that they were interested in screening were entered into the Trial which meant that there was reduced variability in the perceived risk measure. Perhaps, as a consequence of this, there was not a significant relationship between perceived risk and screening attendance (Sutton et al., 2000). While interest or intention is not as robust an outcome as behaviour, it is still important as intention has consistently been found to be positively associated with cancer screening behaviours (Montano & Taplin, 1991; Myers, Balshem, Wolf, Ross, & Millner, 1993; Lechner, de Vries, & Offermans, 1997).

## 2.6. Can optimistic beliefs about cancer be modified?

Relatively few attempts have been made to modify optimistic cancer risk perceptions, even within breast cancer research. A study by Lipkus, Klein and Rimer (2001) assessed the impact of giving individuals their objective breast cancer risk, based on Gail Model scores, on measures of absolute risk and found that after receiving the feedback women adjusted their risk estimate to be more in line with their true risk. Because an absolute measure of perceived risk was used, there was no evidence of women underestimating their risk (having optimistic beliefs) and the feedback worked by reducing their overestimations. This study did not assess the impact on comparative risk and so it was not possible to determine whether comparative optimism had been reduced.

In the bowel cancer literature, providing information on risk factors for bowel cancer has successfully increased perceived risk (Lipkus et al., 1999; Lipkus, Green, & Marcus, 2003). Measures of both comparative and absolute perceived risk were significantly greater after participants had read the risk information. The studies by Lipkus and colleagues sought to determine which factors caused perceived risk to increase, however they found that all information increased perceived risk. Providing risk factor information (age and polyps[5]) versus comparing the incidence of bowel cancer with other cancers did not have a differential impact on perceived risk (Lipkus et al., 1999). A second study, providing information on the prevalence of bowel cancer relative to other cancers and risk factors

[5] Polyps are small growths on the bowel wall which can develop into cancer.

(age and polyps) versus reading about treatment and its consequences along with patient testimonials, similarly failed to show a differential impact on perceived risk (Lipkus et al., 2003). This suggests that although we know that it is possible to increase perceptions of risk, we don't know precisely what information is causing the shift. It is also not apparent from the results of these studies whether the manipulations worked by reducing the proportion of people with optimistic beliefs and shifting them to perceive their risk as average, or by increasing the proportion of people with pessimistic beliefs i.e. shifting those who regard their risk as average to perceiving their risk as higher than average[6].

The studies by Lipkus et al. suggest that perceptions of bowel cancer risk can be changed. However, the samples used were not representative – they were predominantly white and highly educated, and were recruited through advertisements in newspapers.

Results from the UK FS Trial showed that providing brief information about bowel cancer along with information about the future introduction of screening led participants to be more comparatively optimistic compared to those who were given no information (Wardle, Taylor, Sutton, & Atkin, 1999). This is contrary to the prediction that raising awareness that bowel cancer is common should increase perceived risk. However, it may be that informing people about the possibility of screening allows them to feel more optimistic and to see bowel cancer as less of a threat (as would be predicted from the Fear-drive Model, Hovland et al., 1953). Thus the net effect of combined risk factor information and screening information may obscure the two separate effects. It therefore seems worthwhile to further explore the differential impact of giving risk factor information, and risk factor plus screening information.

Trying to change people's perceptions of their personal risk is difficult (e.g. Weinstein & Klein, 1995). However, changing perceptions of risk for a relatively unfamiliar threat (such as bowel cancer in the UK (McCaffery et al., 2003)) may be easier than attempting to change perceptions of risk for more familiar risk (Weinstein & Klein, 1995). In terms of this thesis, it may be possible to intervene to reduce optimistic beliefs about bowel cancer,

[6] I contacted the first author about this point and he suggested (from memory) that the manipulation worked by making people more pessimistic rather than less optimistic (i.e. those whose previous judgments were 'average risk' shifted to 'higher than average' rather than those whose judgements were 'lower than average' shifting to 'average'.

but at present there is insufficient knowledge about how people perceive their personal risk for bowel cancer, particularly in the UK population. If one were to attempt to reduce optimistic beliefs, it would be essential to understand the determinants of the optimistic beliefs so that these could be challenged.

In 1999 the Journal of the National Cancer Institute devoted a Monograph to risk perception and risk communication. One of the main conclusions suggested by Marcus (1999) within the Monograph was that there should be more research testing interventions to debias optimistic beliefs. In particular Marcus highlighted the possibility of targeting attributions of risk in achieving this goal. Lerman, Rimer and Glynn (1997) also highlighted enhancing risk communication, comprehension and informed decision making for cancer prevention and cancer screening as a priority for behavioural research.

This chapter has provided an introduction to risk perception and comparative optimism in the cancer literature. It has shown that people tend to be optimistically biased in estimating their chances of developing cancer. However, no study has focused on perceptions of risk for bowel cancer in a population sample or in a country other than the US. Few studies have been able to examine the relationship between comparative perceived risk and clinical endpoints, and doing so may inform us to whether people are truly 'unrealistic' in their estimations of personal risk. Finally, it may be possible to reduce optimistic beliefs in an attempt to promote cancer-preventive behaviours, but there has been insufficient work examining how to change perceptions of risk for bowel cancer for any strong conclusions to be drawn.

# CHAPTER 3

## Screening for bowel cancer

### 3.1. Bowel cancer

Bowel cancer is the lay term used to describe cancer of the colon and rectum (sometimes referred to as colorectal cancer). It is the second leading cause of cancer death in the UK (Quinn et al., 2001) and the second most commonly diagnosed in the developed world (Parkin & Muir, 1992). For a person living in the UK, the average lifetime risk of developing bowel cancer is around 5% (Quinn et al., 2001).

In line with most other cancers, bowel cancer is unevenly distributed throughout the world, and is much more prevalent in developed countries. Twin and migration studies suggest that the large majority of cancers are caused by environmental rather than genetic factors (Willett, 2002). Some migrant studies have shown that changes in bowel cancer risk can occur within 10-15 years, even in adults (Haenszel & Kurihara, 1968; McMichael, McCall, Hartshorne, & Woodings, 1980).

That cancers are caused by the environment is not a new finding. As early as the 1960's, cancer epidemiologists had concluded that many cancers were preventable if individuals chose the right lifestyle and environment (WHO, 1964), and approximately 90% of bowel cancers were judged to be preventable by life-style modification (Doll & Peto, 1981).

### 3.2. Risk factors for bowel cancer

Two non-modifiable risk factors for bowel cancer are age and gender. Age is the largest single risk factor with incidence increasing rapidly after 50 years of age. Being male also increases the chances of developing bowel cancer with a male: female ratio of age-

standardized rates of 1.5: 1.0 (Quinn et al., 2001). Colditz et al. (2000) proposed the Harvard Cancer Risk Index to provide a broad classification of cancer risk based on group consensus among researchers at the Harvard Medical School and Harvard School of Public Health. The Harvard Cancer Risk Index identifies modifiable risk factors as definite, probable and possible causes of cancer. Table 3.1 describes the exposures they identified for colon cancer and is a reproduction of the information they present in their paper (Colditz et al., 2000; p.481, Table 4). The 'definite' factors increasing risk include; having a first degree relative with bowel cancer, having a body mass index of greater than 27, and having a history of inflammatory bowel disease. The factors thought to definitely decrease risk include; screening, taking aspirin and folate. 'Probable' factors increasing risk were; alcohol, height over 6 feet, and red meat consumption, while 'probable' factors decreasing risk included; vegetable consumption, physical activity, oestrogen replacement, and taking the oral pill. Factors thought to have a 'possible' increasing risk effect were saturated fat and smoking, and 'possible' decreasing risk factors were fruits and fibre. Recently, Kim, Rockhill and Colditz (2004) tested the validity of the Harvard Cancer Risk Index over a period of 10 years' follow-up and found the Risk Index to be well correlated with observed relative risks for colon cancer in women, while it performed moderately for colon cancer in men.

Table 3.1 illustrates some of the ways in which people may be able to avoid developing bowel cancer. Realistically, it is unlikely (for the foreseeable future) that the population would engage in such lifestyle changes to the extent that bowel cancer was totally prevented. Until such time that cancers can be either entirely prevented or easily cured, the best hope for reducing mortality lies in detecting disease at an early or precancerous stage so that the oncogenic process can be interrupted at the earliest possible time (Breen, Wagener, Brown, Davis, & Ballard-Barbash, 2001).

**Table 3.1 Risk exposures for bowel cancer taken from Colditz et al. (2000, .p481, Table 4)**

| Strength of evidence | | | | | |
|---|---|---|---|---|---|
| *Definite*: An association has been established between the exposure and outcome, in which chance, bias and confounding can be ruled out with reasonable confidence | | *Probable*: An association has been observed between the exposure and the outcome but chance, bias and confounding cannot be ruled out with reasonable confidence | | *Possible*: The available studies are of insufficient quality, consistency or statistical power to permit a conclusion of probable or definite association between exposure and outcome | |
| | Relative risk | | Relative risk | | Relative risk |
| Family history (FDR) | 1.8 | **Vegetables** | 0.7 | **Fruits** (upper quartile vs. lower quartile) | 0.8 |
| **Obesity** (>27 BMI vs. < 21) | 1.5 | **Alcohol** (>1 drink/day vs. 0) | 1.4 | **Fibre** (upper quartile vs. lower quartile) | 0.7 |
| **Screening** (FOBT or FS vs. none) | 0.5 | Height (6" increment) | 1.3 | **Saturated fat** (upper quartile vs. lower quartile) | 1.4 |
| **Aspirin** (15 years of regular use) | 0.7 | **Physical activity** (≥3h/week vs. none) | 0.6 | **Smoke** (≥25 cigarettes/day vs. none) | 1.5 |
| **Folate** | 0.5 | Estrogen replacement (≥5 yrs vs. 0) | 0.8 | | |
| Inflammatory bowel disease (Crohn's disease, ulcerative colitis or pancolitis; diagnosed for more than 10 years) | 1.5 | Oral contraceptive use (≥5 yrs vs. 0) | 0.7 | | |
| | | **Red meat** (upper quartile vs. lower quartile) | 1.5 | | |

Modifiable factors are in **bold**

Abbreviations: FDR=first degree relative; BMI=body mass index; FOBT=faecal occult blood test; FS=flexible sigmoidoscopy.

### 3.3. Natural history of bowel cancer

More than 95% of bowel cancers develop from adenomatous polyps (Yood et al., 2003). This means that they progress from small, harmless polyps in the bowel wall to cancerous lesions. The earlier bowel cancer is detected the easier it is to treat. Bowel cancers are categorised according to the Duke classification which is as follows:

Duke's A – the cancer is only affecting the innermost lining of the colon or rectum.
Duke's B – the cancer has grown into the muscle layer of the colon or rectum.
Duke's C – the cancer has spread to at least one lymph node in the area.
Duke's D – the cancer has spread to somewhere else in the body such as the liver or lung.

A problematic feature of bowel cancer is that it is frequently asymptomatic until an advanced stage, and when symptoms do appear they may be mistaken for a less serious condition. This means by the time people seek help for bowel symptoms, the cancer is likely to be advanced and prognosis is poor. Around 29% of cancers are diagnosed at Duke's stage D which has a five year survival of only 3%. If detected at an early stage (Duke's stage A), five year survival is 83%. It is also possible to detect the pre-malignant adenomatous polyp when treatment is effective in almost 100% of cases (Atkin, Morson, & Cuzick, 1992).

While survival statistics provide some evidence of the benefits of early detection, it is important to consider the possible effects of lead-time bias. For example, if the natural history of a disease is 10 years from beginning to its fatal end, and if symptoms appear after 5 years which prompts the person with the disease to seek help from a doctor; the survival time from symptomatic diagnosis is five years. If the disease is detected earlier in the pre-symptomatic phase via a screening test at e.g. three years, survival time will have apparently increased. However, detecting the disease at an earlier stage does not necessarily mean survival has been increased; only that the person is aware of it for longer. Therefore a randomised controlled trial with mortality rates as the outcome measure is the appropriate way to assess the benefit of diagnosing a disease at an earlier stage.

## 3.4. Screening for bowel cancer

### *3.4.1. Definition and screening criteria*

Screening refers to detecting a disease or pre-disease in people who are presumed or presume themselves to be healthy (Holland & Stewart, 1999). The National Screening Committee (2000) define screening as:

> *"A public health service in which members of a defined population, who do not necessarily perceive they are at risk of, or are already affected by, a disease or its complications, are asked a question or offered a test to identify those individuals who are more likely to be helped than harmed by further tests or treatment to reduce the risk of disease or its complications."*

Before any screening test or programme is introduced it should meet the following criteria proposed by Wilson and Jungner (1968):

1. The disease
    a. An important problem
    b. Recognisable at the latent or early symptomatic stage
    c. The natural history must be understood (including development from latent to symptomatic stage)
2. The screen
    a. Suitable test or examination (of reasonable sensitivity and specificity)
    b. Test should be acceptable by the population being screened
3. Follow-up
    a. Facilities must exist for assessment and treatment
    b. Accepted form of effective treatment
    c. Agreed policy on whom to treat
4. Economy
    a. Cost must be economically balanced in relation to possible expenditure on medical care as a whole

It seems likely that bowel cancer screening would meet all of the above criteria. Criterion 1 is certainly met: bowel cancer is the second most common cause of cancer death in the UK; it can be detected while still asymptomatic; the adenoma-carcinoma sequence is understood. Criterion 2 is also met for faecal occult blood (FOB) testing and flexible sigmoidoscopy (FS). Ongoing trials of bowel cancer screening will confirm whether criteria 3 and 4 are also true.

### *3.4.2. Screening tests for bowel cancer*

There is a growing body of evidence that screening for early stage colorectal cancers or pre-cancerous adenomas could reduce bowel mortality (Newcomb et al., 2003; Winawer et al, 1987; Mandel et al, 1993). It is estimated that if screening were performed to a high standard and sufficient numbers of the population participated; bowel cancer mortality would drop by approximately 15% using FOB testing (Hardcastle et al., 1996; Krongborg, Fenger, Olsen, Jorgensen, & Sondergaard, 1996), and 30% for FS (Robinson & Hardcastle, 1998), and some estimates for FS are even higher at 60%-80% (Newcomb et al., 2003).

The three main methods of bowel screening are FOB test, FS and colonoscopy. The FOB test examines stool samples for blood as this is an early sign of cancer in the bowel. If blood is detected, the individual is referred for colonoscopy. Cancers, and some large polyps, bleed in the bowel and the FOB test is able to detect this blood which is hidden or 'occult' to the human eye. The advantage of FOB testing is that it detects cancer at an earlier, pre-symptomatic stage and therefore improves prognosis.

The FS test involves having a thin tube, with a tiny camera on the end to visualise the bowel, inserted in the back passage. Participants are conscious throughout the procedure and can watch on a video screen. The test looks for polyps, growths on the bowel wall which have been described as resembling 'cherries on stalks'. With minimal discomfort pre-malignant adenomas/polyps can be snared and removed by passing a thin wire through the sigmoidoscope, thus interrupting the adenoma-carcinoma sequence. Screening by FS therefore not only has the advantage of being able to detect early stage cancers but can also detect and remove pre-cancerous adenomas and prevent the development of cancer. The sensitivity (90%) and specificity (99%) figures for FS are similar to those for colonoscopy.

The FS test only examines the distal colon but if the proximal (the upper part of the bowel) or right side of the colon need to be investigated a colonoscopy will be used. FS screening has been recommended in the US since the 1980s, and the substantial decrease in bowel cancer incidence has been attributed to the widespread use of sigmoidoscopy and polypectomy (removal of pre-cancerous adenomatous polpys; Nelson, Persky, & Turyk, 1999). During the same period, bowel cancer incidence has increased in the UK (Quinn et al., 2001).

Colonoscopy is similar to FS in that it allows direct visualisation of the bowel. The major advantage of colonoscopy is that it examines the entire bowel. Similar to the FS test, polyps can be removed during the procedure by passing a wire loop through the colonoscope to cut the polyp from the bowel wall using an electric current. While colonoscopy provides the most thorough examination, it is an expensive procedure and the patient requires some sedation.

### 3.5. Bowel cancer screening in the UK

The Secretary of State for Health announced in October 2004 that a national bowel screening programme was to be rolled out across the country by April 2006. This announcement follows two large-scale pilot trials of FOB and FS testing in the UK. FOB testing will be extended beyond the pilot centres in April 2006 and in the meantime, a further pilot of FS screening will be completed to contribute to decision-making about the most cost-effective screening technologies. Introducing screening is not necessarily enough to achieve high levels of uptake. Data from the United States, where bowel screening has been available for many years, shows very poor uptake rates (CDC, 2001). There is concern that we could see the same problem in the UK (Wardle et al., 2000; Wardle, Williamson, McCaffery et al., 2003).

This thesis is therefore investigating an area which has the potential for considerable practical application. With screening strategies that have been proven to reduce risk, attention turns to understanding how to maximise screening utilization, since screening

programmes can only be effective public health tools if people use them in sufficient numbers.

### 3.6. UK FS Trial

Studies 1, 2 and 3 in this thesis used data from the UK FS Trial. The FS Trial is a randomised controlled trial of the efficacy of once-only FS in adults aged 55-64 years (Atkin et al., 2001; UK Flexible Sigmoidoscopy Screening Trial Investigators, 2002). Approximately, 350,000 men and women were randomised to attend screening or to the control group in the ratio 1:2. The Trial was conducted in 14 centres throughout the UK (Welwyn Garden City, Leicester, Glasgow, Swansea, Harrow, Liverpool, Newport, Norwich, Portsmouth, Manchester, Leeds, Newcastle, Oxford and Birmingham). All screening was completed by August 1999. A 10 year follow-up will examine differences in morbidity and mortality between the screened and control groups.

Various psychosocial research questions were addressed in the FS Trial and around 40,000 participants completed questionnaires with a range of psychological and demographic questions. The pre-screening background questionnaire completed by participants in Glasgow, Harrow, Welwyn Garden City, Leicester, Leeds and Birmingham, assessed predictors of interest in attending FS screening. Studies 1 and 3 used data from this subset of trial participants. Other questionnaires sent to different centres examined the efficacy of an intervention booklet designed to increase uptake in FS screening (Wardle, Williamson, McCaffery et al., 2003) and the psychological impact of screening (Wardle, Williamson, Sutton et al., 2003).

The pre-screening background questionnaires completed at the 5 different centres measured broadly the same variables. However, there was some variability between centres, for example, Welwyn Garden City, Leicester and Glasgow measured components of the Health Belief Model (Rosenstock, 1974), while Birmingham tested the Self Regulatory Model (Leventhal et al., 1980) and Leeds and Harrow tested the Theory of Planned Behaviour (Ajzen, 1991). Study 2 used data from all those participants who had been randomised to screening and who had completed a psychosocial questionnaire prior to receiving their screening invitation.

Studies 1, 2 and 3 are therefore secondary analyses of the FS Trial data. Perceived risk had not been considered in-depth before in this dataset, and I was keen to explore perceptions of risk in relation to a health issue that had practical implications. The data from the UK FS Trial gave me this opportunity, although because it was a secondary analysis there were limitations in the variables available.

The initial months of my PhD were spent preparing the data to address my hypotheses. Assembling the datasets proved to be a complicated and time consuming task due to the complex nature of the Trial data. The Trial data are stored on an Oracle database. In order to access the data required, sql syntax had to be written to download the appropriate data into a format which could then be read by an SPSS file.

Birmingham was the last centre to be assessed and as a result the data were not included on the main Oracle database. Syntax had to be written to add together the Oracle data with the Birmingham data for every variable (n>100). Considerable time was spent cleaning and checking the data to ensure that all the appropriate data had been retrieved from the Oracle database. It was during this process that it was discovered that substantial amounts of postcode data were missing from one of the centres.

The significance of the postcode data is that it was used to link participants' area of residence to information from census enumeration districts to index neighbourhood-level deprivation. This measure of deprivation was my primary objective indicator of socioeconomic status (SES). It was discovered that postcode data were missing for around 1000 participants in Welwyn Garden City which therefore meant that I did not have their objective measure of SES. To rectify this, I obtained the addresses of all those who were missing a postcode and manually looked up each of their addresses in a Postal Address Book to find their postcodes.

# Research Questions

## 3.7. Questions for research

From the literature reviewed it is apparent that little empirical research has focused on perceptions of risk for bowel cancer which is the second highest cause of cancer death in the UK. In this doctoral thesis I will examine 5 key research questions which are relevant both to theory and practice. It is intended that this research will contribute to the understanding of how risk for bowel cancer is perceived.

1. What are people's perceptions of risk for bowel cancer?

The majority of work examining perceptions of risk for cancer have focused on breast cancer, with the few studies considering bowel cancer being limited to specific population subgroups. Determining whether an optimistic bias exists in a UK population-based sample will contribute to the focus of public-health education when nationwide screening is introduced.

2. Are certain subgroups more likely to be comparatively optimistic about their bowel cancer risk?

No studies of perceived risk for bowel cancer have explored its correlates in a population sample. Examining the correlates of perceived bowel cancer risk will allow any mis-matches between perceived and actual risk to be addressed in public-health education.

3. Do perceptions of risk for bowel cancer relate to clinical endpoints?

Previous work in the cancer literature has attempted to assess the accuracy of personal risk appraisals by comparing perceived risks with results from risk algorithms such as the Gail Model for breast cancer. No study in the cancer field has compared perceived risk with a clinical endpoint. Determining whether people have accurate perceptions of their risk will establish whether people need to be better informed about their risk status to encourage more cancer-preventive behaviour.

4. To what extent does Weinstein's (1984) five factor framework 'explain' the variance in perceived risk for bowel cancer?

The five categories proposed by Weinstein (1984) based on individuals' reasons for their risk judgements provide a useful framework in which to study the correlates of risk perception. No study has, to my knowledge, assessed the extent to which the five factors in combination 'explain' the variation in perceived risk. This approach will provide an important insight into the determinants of perceived risk.

5. Can perceptions of risk for bowel cancer be changed?

Risk perceptions are notoriously difficult to change (Weinstein & Klein, 1996). Few studies have attempted to debias risk perceptions in a large population sample. Discovering whether risk perceptions for bowel cancer can be changed will provide vital information for the design of public-education strategies when bowel cancer screening is introduced.

The present doctoral thesis investigated these five research questions in a series of six studies.

Study 1: was a quantitative study nested in the UK FS Trial data. The study examined people's perceptions of risk for bowel cancer and then explored the demographic and psychosocial correlates of perceived risk for bowel cancer in a population sample.

Study 2: examined how perceptions of risk relate to clinical outcomes. Using data from the UK FS Trial, perceptions of bowel cancer risk were compared with polyp status found during the FS test.

Study 3: explored the extent to which the Weinstein's (1984) five factors in combination 'explain' the variance in perceived risk using data from the UK FS Trial.

Study 4: was a qualitative study further investigating the factors associated with perceived risk for bowel cancer. Study 4 complemented Studies 1 and 3, but provided a richer and fuller account of the reasons people gave for their risk judgements. Content analysis was used to examine the data.

Study 5: replicated Study 3 in testing the extent to which Weinstein's (1984) five factor framework 'explained' perceived bowel cancer risk using a broader range of measures collected as part of Study 6.

Study 6: was a quantitative intervention study drawing on the findings from studies 1 and 4. The study examined whether giving people simple, accurate information about bowel cancer risk alerted them to their personal risk of developing bowel cancer and increased their interest in attending screening.

# CHAPTER 4

## Study 1: Examining the demographic and health-related correlates of perceived risk for bowel cancer[7]

### 4.1. Introduction

Comparative optimism about the chance of developing cancer is widespread in the literature on breast cancer (e.g. Aiken et al., 1995; Lipkus, Rimer, & Strigo, 1996, Woloshin et al., 1999), and have been seen in the few studies considering bowel cancer (Blalock et al., 1990; Price, 1993; Lipkus, Rimer, Lyna et al., 1996; Vernon et al., 2001). However, few studies have studied comparative optimism using population samples, and the majority of work has been carried out in the US.

Identifying population subgroups who display the most comparative optimism might aid the design of interventions to increase health behaviours. It is difficult to generalise from the work considering demographic correlates of perceived cancer risk because there have been few studies based on representative samples of men and women. One factor which has been consistently related to comparative optimism is older age (e.g. Price, 1993; Grunfeld et al., 2002; Katapodi et al., 2004; Vernon et al. 1993; 2001). Data from some of the centres in the UK FS Trial have found no effect of gender or SES on perceived risk of bowel cancer (Wardle et al., 2000; Wardle et al., 2003). Most work on the relationship between perceived risk and ethnicity suggests that non-white groups tend to be more comparatively optimistic (Skinner et al., 1998; Vernon et al., 2001; Katapodi et al., 2004), however the relationship has not be explored in a UK sample.

In relation to health factors and perceived risk, more comparatively optimistic beliefs have been associated with the absence of a family history, having few symptoms and feeling

[7] A version of this paper was published in *Cancer Epidemiology, Biomarkers & Prevention*, **13**, 366-372, 2004, and is included in Appendix 1.

well, and lower levels of anxiety. People who engage in health behaviours also tend to perceive their risk as lower than average.

The majority of work examining perceptions of risk for cancer has focused on breast cancer, with the few studies considering bowel cancer being limited to specific population subgroups such as African Americans (Lipkus, Rimer, Lyna, et al., 1996) or white, male, automotive industry workers (Vernon et al., 2001). The first aim of Study 1 was to examine whether a population sample of older adults displayed an optimistic bias in judging their chances of developing bowel cancer. It is logically not possible for a population sample as a whole to be at below average risk, so if this is found to be the case then it can be concluded that the sample is demonstrating an optimistic bias. A second aim of Study 1 was to explore the correlates of perceived bowel cancer risk as these have not been examined before in a population sample.

Determining whether an optimistic bias exists in a UK population-based sample, and identifying any inconsistencies surrounding the correlates of perceived risk with what is known from epidemiological data on the true risk factors will contribute to the focus of public health education when nationwide screening is introduced.

### *4.1.1 Hypotheses*

The present study used baseline data from the UK FS Trial to investigate the following hypotheses:

1. Comparative optimism about developing bowel cancer in the future will be observed in a large, community-based sample of older adults.
2. Being older and non-white will be related to lower perceived risk, and gender and socioeconomic status (SES) will not be associated with perceived risk.
3. Family history, subjective health, bowel symptoms, health behaviours and emotional state will be associated with perceived risk for bowel cancer.
4. Comparative optimism will be associated with less interest in bowel screening.

I chose to look at these particular correlates as the measures fit broadly into the five factor framework described by Weinstein (1984) which is based on people's explanations for their risk judgements (this is described in detail in Study 3). They therefore should be important correlates of perceived risk. Because this was a secondary analysis I was limited to the variables available within the UK FS Trial.

## 4.2. Methods

### *4.2.1. Design, participants and procedures*

The design of this study was cross-sectional. None of the participants had been screened in the past, since screening is not otherwise available in the UK. Therefore risk judgements should not be confounded by prior screening behaviour. The data come from the baseline assessment of a subset of the 354,262 participants in the UK FS Trial who were randomized to receive a pre-screening questionnaire. Participants (N=18,447) were men and women aged 55-64 years registered with General Practitioners (GP) in five of the Trial centres (Leicester, Welwyn Garden City, Leeds, Harrow and Birmingham). While data from Glasgow were also available for baseline assessments, they were excluded from these analyses because the Glasgow centre used a different sampling frame and over-sampled lower SES groups (McCaffery et al., 2002).

Lists of names and addresses of men and women in the target General Practices were provided by the Health Authorities. GPs were asked to exclude any patients who were inappropriate for the trial (e.g. already had bowel cancer, recently had sigmoidoscopy, very ill). This resulted in the exclusion of 2% of potential respondents for the Trial as a whole (Atkin et al., 2002). Letters signed by the GPs were sent to the remaining patients, informing them that a trial of bowel cancer screening was due to be set up in their area and requesting that they complete an enclosed questionnaire. An information sheet describing flexible sigmoidoscopy screening was included, along with a prepaid reply envelope. Non-responders were sent a reminder after two weeks. The questionnaire was an eight page instrument which included a range of simple items on demographic factors, family

background, health behaviours, perceived risk, attitudes and expectations, and psychological wellbeing, an example of one of the questionnaires is provided in Appendix 2. Ethical approval was obtained at local Ethics Committees for each centre.

### *4.2.2. Materials*

*Assessing perceived risk.* The two most commonly used methods of assessing perceived risk are absolute measures and comparative measures, and there is currently no 'gold standard' for assessing perceived risk (Diefenbach, Weinstein & O'Reilly, 1993).

A typical absolute numerical question would read, *"Rate your chance of getting breast cancer someday from 0-100%"*. The major disadvantage of using absolute numerical risk measures is that people are poor at expressing their risk in a precise mathematical form (Absetz et al., 2000; Eiser, Eiser & Pauwels, 1993). To answer a numeric absolute risk question requires a degree of numeracy to give a reasonable probability estimate which many people find difficult (Black et al., 1995; Woloshin et al., 1999). In a study assessing not only perceptions of risk for breast cancer but also numeracy skills (e.g. *"Imagine that we flip a fair coin 1,000 times. Out of 1,000 flips, how many times do you think the coin would come up heads? _____ out of 1,000"*), Black et al. found that in 145 highly educated women aged 40-50 years, only 62% met the criteria for numeracy. Studies have also reported that many people do not know the relationship between frequency and percent (Rothman & Kiviemi, 1999; Schwartz, Woloshin, Black, & Welch, 1997; Lipkus, Rimer, & Strigo). Innumeracy is not only restricted to lay people, Gigerenzer (2002) reported that even doctors, with an average of 14 years of professional experience, show shockingly low understanding .

Another drawback of absolute numerical risk scales is the "50% blip". This describes respondents' tendency to use 50% when they have no idea what the answer is, they believe it might or might not happen, *"It's 50/50"* (Fischhoff & Bruine de Bruin, 1999). A further illustration of people's apparent failure to understand absolute risk scales comes from studies finding that people's subjective probability responses for a set of mutually exclusive and exhaustive events often greatly exceed 100% (e.g., Teigen, 1983; Wright & Whalley,

1983; Robinson & Hastie, 1985; Tversky & Koehler, 1994), suggesting that individuals do not realise the additivity constraint, or choose to ignore it (Windschilt, 2003).

Absolute risk questions can also be asked using closed-ended scales (see Evans et al., 1993; Polednak et al., 1991) in which individuals quantify their own personal risk by choosing from Likert '*likely*' response categories e.g. "*very; somewhat; not very; not at all or don't know*". This methodology avoids the difficulties associated with open-ended numeric scales, however translating numerical probabilities into verbal expressions is problematic because people interpret words such as *"likely"* in different ways (Nakao & Axelrod, 1983; Budescu & Wallston, 1985).

The other commonly used measure of perceived risk is the comparative item. This is a widely used measure of perceived risk in Health Psychology which avoids the pitfalls of absolute questions. For this reason the UK FS Trial investigators decided to use a comparative measure of perceived risk.

*Comparative perceived risk.* The perceived risk/comparative optimism item asked: "Compared with other men and women of your age, do you think your chances of getting bowel cancer are: lower; about the same; higher" based on Weinstein (1987). Responses were scored by allocating -1 for "lower" 0 for "about the same" and +1 for "higher". Thus a negative score implies an optimistic bias while a positive number implies a pessimistic bias. In three of the centres (Leeds, Harrow and Birmingham), response options were on a five point scale ranging from "much lower" (-2) to "much higher" (+2). For the main analyses the responses were recoded into a three point scale i.e. "much lower" and "lower" were recoded as "lower" and "higher" and "much higher" were recoded as "higher". Further analyses examined the two response formats to determine if a different pattern of results emerged.

*Demographic characteristics.* Age and gender were known from the health authority records. Additional simple questions were used to assess ethnicity, "Which of these best describes your ethnic background?" ("White; Black; Asian; Other; do not wish to answer"); and marital status, "What is your marital status?" ("Married/living as married; Divorced; Separated; Widowed; Single").

Individual socioeconomic deprivation was measured by a score composed of three demographic items. "Does your household have a car?" ("yes; no"); "Do you own or rent your home?" ("own it/buying it; rent it; other"); and "Do you have any educational qualifications?" ("yes; no"). Car ownership and housing tenure were selected because they are frequently used markers of deprivation and are included in some of the most widely endorsed indices of deprivation (Townsend, Phillimore, & Beattie, 1988; Carstairs & Morris, 1989). Education is a widely used marker of deprivation, and has the advantage of remaining stable over time unlike other measures. Education also has the advantage of being applicable to those outside the workforce and may be related to health beliefs, values and behaviour (Locker, 1993). One 'deprivation' point was given for each of the following; the household not owning a car; not owning the home and having no educational qualifications. This resulted in the individual deprivation score ranging from 0-3 with 0 representing the most affluent group and 3 the most deprived group.

Postcode data were used to link participants' area of residence to information from census enumeration districts (based on an average of around 460 residents) to index neighbourhood-level deprivation (the Townsend Material Deprivation Index; Townsend et al., 1988) using data from the 1991 census (Crown Copyright, 1991). The Townsend Index incorporates several indicators of socioeconomic deprivation including: unemployment, overcrowding, non-car ownership and non-home ownership. One disadvantage of using area-level deprivation in an older age group is that the area may have changed since they set up home (Grundy & Holt, 2001). A Townsend score of zero represents the national average, negative values represent below-average levels of deprivation, and positive values represent higher than average deprivation. The Townsend Index provided an external validity check to the individual deprivation score and also allowed comparisons to be made between responders and non-responders. For the purposes of analyses, the Townsend Index score was divided into quartiles.

*Family history.* Participants' awareness of a family history of bowel cancer in FDRs was assessed with the question, "Have any members of your family (BLOOD relatives, not relatives by marriage) had bowel cancer?" Options were mother; father; son(s), daughter(s), sister(s), brother(s) with participants asked to indicate "yes; no; don't know; not applicable"

for each relative. These responses were coded into categories of none, one, and two or more. A recent study determining the accuracy of self-reported family cancer history information confirmed that patient-reported family history of colon cancer was accurate for first degree relatives (Murff, Spigel, & Syndal, 2004).

*Health behaviours.* Health behaviours were assessed with two single items which asked if participants smoked or took regular exercise. The smoking question asked, "Do you smoke cigarettes at all nowadays?" (Health Survey for England, 1996) and the exercise question asked, "Do you take regular exercise each week?". Response options were "yes" or "no".

*Bowel symptoms and subjective health.* Bowel symptoms over the past three months were assessed with a list of 7 symptoms (constipation, haemorrhoids, diarrhoea, wind, pains in abdomen, incontinence, blood in stools). Symptom frequency was rated as "no; occasionally; frequently". A total symptoms score (possible range 0-7) was calculated by totaling the number of symptoms that were experienced occasionally or frequently. Subjective health was assessed with the item, "Would you say that for someone of your age your own health in general is: excellent; good; fair; poor" (Health Survey for England, 1996).

*Anxiety.* State anxiety was recorded with the shortened, 6-item version of the Spielberger State Trait Anxiety Inventory (STAI; Spielberger, 1983; Marteau & Bekker, 1992). Respondents were asked to indicate on a four-point Likert type scale ranging from "not at all" to "very much" how they feel right now; calm, tense, upset, relaxed, content, worried. Internal reliability of the STAI was high with a Cronbach's $\alpha$=.83.

*Interest in bowel screening.* Screening interest was assessed with a single question, "If you were invited to have the bowel cancer screening test, would you take up the offer?" The response options were "Yes, definitely; yes probably; probably not; definitely not".

### *4.2.3. Analysis of results*

Results were analyzed using SPSS (Version 10.1). Independent-samples t-tests were used to assess differences in Townsend Index scores and age between respondents and non-

respondents. One-Sample t-tests were employed to examine whether the mean Townsend Index score for respondents was significantly different from 0 which represents the national average. Spearman's rho was used to assess the relationship between the individual deprivation score and the Townsend score. One-Sample t-test were also used to detect an optimistic bias in perceived risk with a significant deviation from the midpoint 0 (the score representing average risk). This is the statistical technique which is commonly used in the literature to test for optimistic bias. However, because perceived comparative risk is not a continuous variable it will only provide an extremely crude approximation. I will use One-Sample t-tests to detect optimistic bias throughout this thesis but I acknowledge that there are limitations to the validity of the results.

Linear trends in proportions across perceived risk categories were assessed with SPSS linear-by-linear Chi square tests (a measure of linear associations between the row and column variables in a cross-tabulation). Linear trends were examined between demographic characteristics and health-related factors in relation to perceived risk. They were also used to assess the relationship between perceived risk and interest in bowel screening.

Univariate and multivariate ordinal logistic regression were used to determine the association between perceived risk, demographic factors and health-related factors. Univariate ordinal regressions were carried out to provide direct comparison with the multivariate ordinal regression. Multiple regression was considered not to be appropriate as the dependent variable (perceived risk) had only 3 categories and multiple regression is not recommended if the dependent variable has fewer than 5 categories (Cohen, Cohen, West, & Aiken, 2003). Similarly, collapsing the dependent variable into a dichotomous variable for logistic regression would result in a loss of information. Ordinal logistic regression is an extension of logistic regression to the analysis of ordered category dependent variables. Categories, organised in ascending order, are assumed to reflect an underlying continuum, and movement from one category to the next indicates that a threshold of the continuum has been crossed. Differences between thresholds are not necessarily equally spaced. Ordinal logistic regression models the odds of transition across thresholds, given values on the predictor variables. That is, it is assumed that the predictors have the same impact on crossing all the thresholds (Cohen et al., 2003). In ordinal

regression one value (typically the first or last) is designated as the reference category and the probability of membership in other categories is compared to the probability of membership in the reference category (Menard, 2002).

It is recognized that in a sample as large as this it is not appropriate to put too much emphasis on statistical significance. However, significance will still be reported and results showing practical significance highlighted.

## 4.3. Results

### *4.3.1. Respondents vs. non-respondents*

The response rate for the baseline questionnaire was 61% ($n$=11,254). Townsend Material Deprivation scores were available for 18,343 participants. Those who returned the questionnaire came from neighbourhoods with significantly lower Townsend scores ($M$=-0.009 $SD$=3.08) than non-respondents ($M$=0.89 $SD$=3.17), ($n$=7193, $t$(18341)=19.01, p<0.001), indicating that they lived in less socioeconomically deprived areas. However, in terms of population levels of deprivation, respondents were roughly representative of England and Wales where the national average Townsend score is zero, which is not significantly different from the mean of the present sample ($t$(11196)=-0.32, p=0.749). Townsend scores for the area of residence showed a significant association with the individual deprivation score, with a correlation of Spearman's rho=0.35, p<0.001. Respondents were also very slightly younger ($M$=60.07, $SD$=2.89) than non-respondents ($M$=60.62, $SD$=3.15; $t$(11392)=3.88, p<0.001).

### *4.3.2. Demographic characteristics*

More women (54%) than men (46%) returned the baseline questionnaire. Respondents were predominantly white (92%) and married (73%), with a mean age of 60 years. The demographic characteristics of the sample are described in Table 4.1. Because the ethnic subgroups of Black, Asian and Other were small, these groups were combined into a 'non-

white' group for subsequent analyses. Marital status was also dichotomized into 'married/living as married vs. non-married' for subsequent analyses.

The individual deprivation index had very few participants (7%) in the most deprived group and a disproportionate number (37%) in the second most affluent group, see Table 4.1. The Townsend score represented quartiles of the sample and so had roughly equal numbers across the four groups.

The demographic characteristics of the sample were compared with those of 55-64 year olds in England and Wales taken from the 2001 Census (ONS, 2004). The two distributions were similar suggesting the current sample was representative of the population.

*Missing data.* The demographic measures had very little missing data, ranging from 0% for gender (obtained directly from the health authority records) to 3.4% for ethnicity. Ethnicity and marital status both had 3% of data missing. The individual deprivation score had 8% of data missing, this was due to participants having to answer all three deprivation marker questions in order to be included in the scale. The Townsend score had little missing data (0.5%). The two major causes of missing Townsend Index data were: inaccurate Health Authority records and individuals living in new houses for whom Townsend Index scores had not yet been calculated.

**Table 4.1: Demographic characteristics of the sample**

| | n (N=11254) | % |
|---|---|---|
| Gender | | |
| Female | 6131 | 54.5 |
| Male | 5123 | 45.5 |
| Missing | 0 | 0 |
| Age | | |
| 55-59 years | 5416 | 48.1 |
| 60-64 years | 5526 | 49.1 |
| Missing | 312 | 2.8 |
| Ethnicity | | |
| White | 10354 | 92.0 |
| Black | 130 | 1.2 |
| Asian | 217 | 1.9 |
| Other | 53 | 0.5 |
| Do not wish to answer | 122 | 1.1 |
| Missing | 378 | 3.4 |
| Marital status | | |
| Married /living as married | 8240 | 73.2 |
| Divorced | 957 | 8.5 |
| Separated | 183 | 1.6 |
| Widowed | 886 | 7.9 |
| Single | 641 | 5.7 |
| Missing | 347 | 3.1 |
| Individual deprivation score | | |
| 1 (affluent) | 2792 | 24.8 |
| 2 | 4128 | 36.7 |
| 3 | 2640 | 23.5 |
| 4 (deprived) | 801 | 7.1 |
| Missing | 893 | 7.9 |

Table 4.1 continued

| | n (N=11254) | % |
|---|---|---|
| Townsend score | | |
| 1 (affluent) | 2785 | 24.7 |
| 2 | 2979 | 26.5 |
| 3 | 2809 | 25.0 |
| 4 (deprived) | 2623 | 23.3 |
| Missing | 58 | 0.5 |

*4.3.3. Comparative optimism*

Overall, respondents showed the predicted tendency to be optimistic about their chances of developing bowel cancer, with the mean for the sample deviating significantly below zero ($M$=-0.08 $SD$=0.50), $t$(10758)=-16.57; p<0.001), see Table 4.2. Table 4.2 also highlights that giving respondents different numbers of response options has little impact on the pattern of results. When the 5-point scale was recoded into a 3-point scale the mean for perceived risk was very similar to those who responded on a 3-point scale originally ($M$=-0.08 $SD$=0.54 vs. $M$=-0.09 $SD$=0.41)

**Table 4.2: Testing for optimistic bias**

| | Mean (SD) of comparative perceived risk | t | df | Significance |
|---|---|---|---|---|
| **Total sample (3 and 5- point scales combined) (n=11254)** | **-0.08 (0.50)** | **-16.57** | **10758** | **p<0.001** |
| 3 - point scale respondents (n=3474) | -0.09 (0.41) | -11.97 | 3283 | p<0.001 |
| 5 - point scale respondents (n=7780) | -0.12 (0.74) | -14.55 | 7474 | p<0.001 |
| 5 – point scale recoded into 3 point scale (n=7780) | -0.08 (0.54) | -12.49 | 7474 | p<0.001 |

For the sample as a whole, 16% thought their chance of getting bowel cancer was lower than other men or women of their age, 71% thought it was about the same, and 8% thought their risk was higher, see Table 4.3. Table 4.3 also shows the breakdown of results for the

centres measuring comparative risk on a three-point scale and those centres using five response options. In the three centres where five response options were given to the comparative risk question, the results were broadly similar with 7% rating their risk as "much lower", 11% as "a little lower", 68% as "about the same", 8% as "a little higher" and 2% as "much higher". When the 5-point scale was recoded into a 3-point scale, respondents showed a broad range of responses and were both more optimistic (18% vs. 12%) and more pessimistic (10% vs. 4%) than respondents completing the 3-point scale.

**Table 4.3: Comparative risk judgements**

| Perceived risk response | (n) | % |
|---|---|---|
| **All respondents (3 and 5- point scales combined) (n=11254)** | | |
| **Lower (-1)** | **1815** | **16.1** |
| **About the same (0)** | **7990** | **71.0** |
| **Higher (+1)** | **954** | **8.5** |
| **Missing** | **495** | **4.4** |
| 3-point scale respondents (n=3474) | | |
| Lower (-1) | 433 | 12.5 |
| About the same (0) | 2701 | 77.7 |
| Higher (1) | 150 | 4.3 |
| Missing | 190 | 5.5 |
| 5-point scale respondents (n=7780) | | |
| Much lower (-2) | 526 | 7.0 |
| A little lower (-1) | 856 | 11.5 |
| About the same (0) | 5289 | 68.0 |
| A little higher (+1) | 637 | 8.2 |
| Much higher (+2) | 167 | 2.1 |
| Missing | 305 | 3.9 |
| 5-point scale respondents recoded into 3-point scale (n=7780) | | |
| Lower (-1) | 1382 | 17.8 |
| About the same (0) | 5289 | 68.0 |
| Higher (1) | 804 | 10.3 |
| Missing | 305 | 3.9 |

### *4.3.4. Associations between demographic factors and perceived risk*

19% of men saw their risk of developing bowel cancer as lower than their peers compared to 15% of women, see Table 4.4, and 8% of men saw their risk as higher than average compared with 10% of women.

Age differences were also significant but very small; in the older age group (60-64 years), 18% of respondents saw their bowel cancer risk as lower, compared to 16% in the younger age group (55-59 years). 10% of those in the younger age group (55-59 years) saw their risk as higher than their peers compared to 8% in the older age group.

Marital status was not significantly related to perceived risk. Married participants showed a slight tendency to be less optimistic (17%) than respondents who were not married (18%). However the reverse was true for higher perceived risk with married participants (8%) less likely to report being at higher risk than those who are not married (11%).

Twice as many non-white (32%) as white (16%) respondents saw their risk of bowel cancer as less than their peers. Non-white respondents were slightly more likely to see their risk as higher compared to white respondents (10% vs. 9%), however this difference was so small it is likely that it was the difference in optimistic beliefs that caused the significant difference.[8]

The individual deprivation score showed a significant difference in risk perception across socioeconomic groups, with socioeconomically deprived respondents reporting feeling at greater risk. The most affluent group showed greater optimism about bowel cancer risk (20% were comparative optimists) than the most deprived group (16%), see Table 4.4. Using the Townsend Index score similarly showed more deprived groups to judge their risk to be higher although the effect was not significant.

[8] To explore this further I recoded the comparative perceived risk scale to combine "the same" and "higher" groups and compared this group to those who saw their risk as "lower". The difference between white and non-white was significant ($\chi^2(1,10447)=70.26$, $p<0.001$). However, when I combined the groups "lower" and "the same" and compared this group with the "higher" group there was not a significant difference. This confirms that the non-white respondents were significantly more optimistic than the white respondents.

**Table 4.4: Demographic influences on perceived risk of bowel cancer (univariate analyses: row percentages)**

| | Perceived risk | | | Significance |
|---|---|---|---|---|
| | Lower | The same | Higher | |
| All respondents (n=11254) | 16.9 | 74.3 | 8.9 | |
| Gender | | | | |
| Female (n=5863) | 15.3 | 74.9 | 9.7 | |
| Male (n=4896) | 18.7 | 73.5 | 7.8 | $\chi^2(2, 10759)=28.8, p<0.001$ |
| Age | | | | |
| 55-59 years (n=5188) | 15.7 | 74.9 | 9.5 | |
| 60-64 years (n=5297) | 17.7 | 74.2 | 8.1 | $\chi^2(1, 10485)=12.1, p=0.001$ |
| Ethnicity | | | | |
| White (n=10066) | 16.2 | 75.0 | 8.8 | |
| Non white (n=381) | 32.5 | 57.5 | 10.0 | $\chi^2(1,10447)=33.8, p<0.001$ |
| Marital status | | | | |
| Married (n=8013) | 16.5 | 75.4 | 8.1 | |
| Not married (n=2582) | 18.2 | 70.8 | 11.0 | $\chi^2(1, 10595)=1.09, p=0.297$ |
| Individual deprivation score | | | | |
| 1 (affluent) (n=2718) | 20.1 | 71.5 | 8.4 | |
| 2 (n=4013) | 15.6 | 76.7 | 7.7 | |
| 3 (n=2574) | 15.3 | 74.1 | 10.6 | |
| 4 (deprived) (n=779) | 15.9 | 73.0 | 11.0 | $\chi^2(1, 10084)=26.32, p<0.001$ |
| Townsend score | | | | |
| 1 (affluent) (n=2678) | 16.7 | 75.5 | 7.8 | |
| 2 (n=28640 | 16.3 | 75.4 | 8.3 | |
| 3 (n=2697) | 17.2 | 74.4 | 8.3 | |
| 4 (deprived) (n=2497) | 17.3 | 71.4 | 11.3 | $\chi^2(1, 10706)=3.0, p=0.085$ |

### *4.3.5. Descriptive statistics for health-related factors*

7% of respondents reported having a family history of bowel cancer among first degree relatives, see Table 4.5. 22% of the sample were smokers and 31% did not exercise

regularly. 58% reported having had more than one bowel symptom in the past 3 months and 55% saw their general health as being "good" or "excellent". The mean level of state anxiety for the sample was $M$=10.61 $SD$=3.87 which represents a lower level of anxiety than previous studies based on pregnant women, student nurses and medical students have found (Marteau & Bekker, 1992).

**Table 4.5: Descriptive statistics for health related factors**

| | n (N=11254) | % |
|---|---|---|
| Family history (first degree relatives only) | | |
| 0 | 8643 | 76.8 |
| 1 | 691 | 6.1 |
| 2+ | 73 | 0.6 |
| Smoking | | |
| Smoker | 2505 | 22.3 |
| Non smoker | 8374 | 74.4 |
| Exercise regularly | | |
| Yes | 7022 | 62.4 |
| No | 3460 | 30.7 |
| Bowel symptoms | | |
| 0, 1 | 4764 | 42.3 |
| 2, 3 | 4344 | 38.6 |
| 4+ | 2146 | 19.1 |
| Subjective health | | |
| Excellent | 1303 | 11.6 |
| Good | 6425 | 57.1 |
| Fair | 2763 | 24.5 |
| Poor | 412 | 3.7 |
| Anxiety | | |
| Low | 3399 | 30.2 |
| Medium | 3572 | 31.7 |
| High | 3902 | 34.7 |

*4.3.6. Associations between health-related factors and perceived risk*

*Family history.* Having a family history of bowel cancer significantly decreased comparative optimism (see Table 4.6). 18% of respondents with no FDR with bowel cancer perceived their risk to be lower than their peers, compared to 11% of those with one FDR, and 3% of those with two or more.

Those with two or more FDR with bowel cancer were more than 5 times more likely to judge their risk as higher than average than those with no family history (33% vs. 6%). While those with one FDR were almost 4 times more likely to estimate their risk as above average than those with no family history (24% vs. 6%).

*Health behaviours.* Both of the measured health behaviours were associated with risk perceptions, see Table 4.6. 13% of smokers perceived their risk to be lower than their peers compared with 18% of non-smokers. 12% of non-exercisers saw their risk as lower compared to 19% of respondents who exercised regularly.

*Bowel symptoms and subjective health.* Fewer bowel symptoms and perceiving health as better were significantly associated with greater bowel cancer optimism, see Table 4.6. 23% of those reporting zero or one bowel symptom perceived their risk as lower than average compared with only 8% of those who had four or more bowel symptoms. 32% of individuals rating their subjective health as excellent were optimistic, compared with 8% of those reporting their subjective health to be poor.

*Anxiety.* Less anxious respondents were more optimistic about their chance of developing bowel cancer relative to their peers. 22% of respondents in the lowest anxiety tertile perceived their risk as lower than their peers compared to 14% in the highest (see Table 4.6).

**Table 4.6: Associations between health-related factors and perceived risk of bowel cancer (univariate analyses: row percentages)**

| | Perceived risk | | | Significance |
|---|---|---|---|---|
| | Lower | The same | Higher | |
| Family history (first degree relatives only) | | | | |
| 0 (n=8345) | 17.8 | 75.5 | 6.4 | |
| 1 (n=665) | 10.7 | 64.8 | 24.5 | |
| 2+ (n=58) | 3.4 | 63.8 | 32.8 | $\chi^2(1, 9068)=195.9$, $p<0.001$ |
| Smoking | | | | |
| Smoker (n=2439) | 12.8 | 76.5 | 10.7 | |
| Non smoker (n=8139) | 18.1 | 73.7 | 8.2 | $\chi^2(1,10578)=45.7$, $p<0.001$ |
| Exercise regularly | | | | |
| Yes (n=6828) | 19.2 | 72.7 | 8.1 | |
| No (n=3369) | 12.4 | 77.5 | 10.1 | $\chi^2(1, 10197)=68.2$, $p<0.001$ |
| Bowel symptoms | | | | |
| 0, 1 (n=4412) | 22.9 | 73.2 | 3.9 | |
| 2, 3 (n=4244) | 15.1 | 76.7 | 8.2 | |
| 4+ (n=2103) | 7.8 | 71.6 | 20.6 | $\chi^2(1, 10759)=565.4$, $p<0.001$ |
| Subjective health | | | | |
| Excellent (n=1251) | 32.2 | 63.1 | 4.6 | |
| Good (n=6257) | 17.5 | 75.4 | 7.0 | |
| Fair (n=2680) | 9.6 | 77.5 | 12.9 | |
| Poor (n=402) | 8.5 | 69.4 | 22.1 | $\chi^2(1, 10590)=414.6$, $p<0.001$ |
| Anxiety | | | | |
| Low (n=3295) | 21.5 | 73.1 | 5.4 | |
| Medium (n=3478) | 15.9 | 76.3 | 7.8 | |
| High (n=3797) | 13.8 | 73.3 | 12.9 | $\chi^2(1, 10570)=161.4$, $p<0.001$ |

*4.3.7 Ordinal regression*

Univariate ordinal logistic regressions were carried out to provide direct comparisons with subsequent multivariate analyses. In line with the results from the linear-by-linear chi-square analysis, the univariate ordinal regressions showed that being male, in the older age group (60-64 years) and non-white were each associated with being more optimistic (see Table 4.7 columns 1 and 2). Those in the lowest individual socioeconomic deprivation group were more pessimistic compared with the most affluent group.[9] Marital status was not significantly related to perceived risk. Those with a family history of bowel cancer were more likely to perceive their risk as higher. Having more bowel symptoms and poorer subjective health were both strongly related to higher perceived risk. Smokers judged their risk to be higher and non-exercisers also regarded themselves at higher risk. Respondent who reported higher levels of anxiety perceived their risk to be higher.

A multivariate ordinal logistic regression was then used to identify the independent predictive effects of each of the variables, while controlling for the other factors (Table 4.7 columns 3 and 4). The odds ratios in the multivariate analysis were very much the same as in the univariate analyses, indicating that each of the factors had effects which were largely independent of one another. One difference was that the effect of individual socioeconomic deprivation became non significant. Upon further analyses it was found that it was the addition of subjective health which caused the individual socioeconomic deprivation score to become non significant.

[9] Only the individual deprivation score was analysed using ordinal logistic regression. One of the assumptions of regression is that predictors should be independent and as was noted above there was a significant association between the individual deprivation score and the Townsend score ($r$=0.364, $p<0.001$). As the Townsend score was not significantly related to perceived risk in the linear-by-linear chi-square analysis it was decided that it should be dropped from further analysis and the individual deprivation score explored using ordinal logistic regression.

**Table 4.7: Univariate and multivariate ordinal regressions of the predictors of perceiving higher risk of bowel cancer (ordered/the same/higher)**

| | Univariate odds ratios of perceived risk | Univariate Significance | Multivariate odds ratios of perceived risk | Multivariate significance |
|---|---|---|---|---|
| Gender | | | | |
| Female | 1.00 | | 1.00 | |
| Male | 0.79 [0.72, 0.86] | p<0.001 | 0.85 [0.76, 0.94] | p=0.002 |
| Age | | | | |
| 55-59 years | 1.00 | | 1.00 | |
| 60-64 years | 0.86 [0.78, 0.94] | p<0.001 | 0.88 [0.79, 0.97] | p=0.011 |
| Ethnicity | | | | |
| White | 1.00 | | 1.00 | |
| Non white | 0.49 [0.39, 0.61] | p<0.001 | 0.48 [0.37, 0.62] | p<0.001 |
| Marital status | | | | |
| Married | 1.00 | | 1.00 | |
| Not married | 1.04 [0.94, 1.16] | p=0.390 | 1.12 [0.79, 1.02] | p=0.086 |
| Individual deprivation score | | | | |
| 0 (affluent) | 1.00 | | 1.00 | |
| 1 | 1.22 [1.10, 1.36] | p<0.001 | 1.08 [0.95, 1.22] | p=0.237 |
| 2 | 1.38 [1.23, 1.56] | p<0.001 | 1.20 [1.04, 1.38] | p=0.015 |
| 3 (deprived) | 1.38 [1.15, 1.65] | p<0.001 | .96 [0.77, 1.21] | p=0.762 |
| Family history (first degree relatives only) | | | | |
| 0 | 1.00 | | 1.00 | |
| 1 | 3.53 [2.94, 4.24] | p<0.001 | 3.41 [2.80, 4.15] | p<0.001 |
| 2+ | 6.63 [3.87, 11.36] | p<0.001 | 5.72 [3.09, 10.60] | p<0.001 |
| Smoking | | | | |
| No | 1.00 | | 1.00 | |
| Yes | 1.43 [1.29, 1.58] | p<0.001 | 1.27 [1.12, 1.44] | p<0.001 |

Table 4.7 continued

| | Univariate odds ratios of perceived risk | Univariate significance | Multivariate odds ratios of perceived risk | Multivariate significance |
|---|---|---|---|---|
| Exercise | | | | |
| Yes | 1.00 | | 1.00 | |
| No | 1.50 [1.36, 1.65] | p<0.001 | 1.27 [1.13, 1.42] | p<0.001 |
| Bowel symptoms | | | | |
| 0, 1 | 1.00 | | 1.00 | |
| 2, 3 | 1.75 [1.59, 1.93] | p<0.001 | 1.60 [1.43, 1.79] | p<0.001 |
| 4+ | 4.72 [4.16, 5.37] | p<0.001 | 3.68 [3.14, 4.30] | p<0.001 |
| Subjective health | | | | |
| Excellent | 1.00 | | 1.00 | |
| Good | 2.13 [5.37, 8.94] | p<0.001 | 1.78 [1.52, 2.07] | p<0.001 |
| Fair | 4.17 [3.59, 4.85] | p<0.001 | 2.85 [2.36, 3.43] | p<0.001 |
| Poor | 6.92 [5.37, 8.94] | p<0.001 | 4.23 [3.06, 5.86] | p<0.001 |
| Anxiety | | | | |
| Low | 1.00 | | 1.00 | |
| Medium | 1.42 [1.79, 2.21] | p<0.001 | 1.14 [1.00, 1.29] | p=0.041 |
| High | 1.99[1.79, 2.21] | p<0.001 | 1.20 [1.05, 1.37] | p=0.007 |

### *4.3.8. The relationship between perceived risk and interest in screening*

As expected, comparative optimists were less interested in screening, see Table 4.8. 73% of those who perceived their risk to be lower than averaged were interested in bowel screening compared with 82% who saw their risk as 'the same' and 95% who viewed their risk as higher than average.

**Table 4.8: The relationship between perceived risk and screening interest**

| | Screening interest | | | | Significance of difference |
|---|---|---|---|---|---|
| | Yes definitely | Yes probably | Probably not | Definitely not | |
| Perceived risk % | | | | | |
| Lower (n=1815) | 43.6 | 29.8 | 17.4 | 9.3 | |
| The same (n=7990) | 51.5 | 31.1 | 12.9 | 4.6 | |
| Higher (n=954) | 79.7 | 15.2 | 3.2 | 1.9 | $\chi^2(1, 10759)=314.1$, $p<0.001$ |

## 4.4. Discussion

Overall, this large sample of older British adults showed modest levels of optimism about their chances of developing bowel cancer, but the proportion of individuals making optimistic judgments was lower than in some other studies – most of which were in the US. 16% of respondents were optimistic about their risk of developing bowel cancer, which is considerably lower than the 36% reported by Lipkus, Rimer, Lyna et al. (1996) for bowel cancer in a telephone survey of American adults older than 50 years, and the almost 50% reported by Aiken et al. (1995) for breast cancer in a questionnaire survey of women aged 37-77 years. Similarly, fewer than 11% of respondents with a family history in our study showed an optimistic bias; substantially lower than among Blalock et al.'s (1990) respondents, of whom 29% of 40-75 year olds with a FDR with bowel cancer saw their risk as lower than their peers.

Why should our respondents show less of an optimistic bias than previous research? One explanation may be the cultural differences in risk perception between the UK and the US, where the majority of the work in this area has been carried out. Only one studied was identified which specifically examined differences in cancer risk perception between America and Britain (Fontaine & Smith, 1995). Forty-three working-class British and 61 lower middle-class Americans made judgments about their own risk of cancer and the average person's risk of cancer, using an unconventional indirect measure of perceived risk. Fontaine and Smith found that British participants were significantly more optimistic than the American participants. I would suggest that the results from Fontaine and Smith are

questionable due to the very small sample sizes and the focus on one population subgroup: the lower social classes. In addition, as the authors state themselves, perceived risk was assessed by a measure of "uncertain reliability and validity". Most other studies comparing other countries to the US have found Americans to be more optimistically biased. When American and Danish college students were asked about comparative risk for unplanned pregnancy, sexually transmitted disease, and HIV, Americans were much more optimistically-biased than Danes (Helweg-Larsen, 1995). Other studies comparing levels of comparative optimism between West and East, represented by North America and Japan, have also found North Americans to display more optimism (Heine & Lehman, 1995; Kitayama, Markus, Matsumoto & Norasakkunkit, 1997). Heine and Lehman (1995) attribute this difference to North American culture having an independent construal of the self while Japanese culture is typical of an interdependent construal of the self. Using this interpretation, it could be suggested that the present study of older UK adults represents a group who are more self-effacing, in the form of seeing oneself as average, than their US counterparts. This interpretation seems plausible given that this group of 55-64 year olds were children during World War 2 and that this cohort is generally considered as being more socially-minded. It is possible that younger generations, who have had more exposure to American ideals and culture, may diverge less from the US-based studies. Future work could consider this hypothesis by comparing perceptions of risk in different age groups within the UK population.

In the words of Kahneman (2003), "Americans are the most optimistic people in the world." Whether this is due to the optimistic ideology of the 'American Dream' which is influential in the American culture or whether the prospects of a better life in the US caused more optimistic people to emigrate to the US leaving the more pessimistic back in Europe, is unclear.

Another possible explanation for the current study finding lower levels of optimism is the context of the present study, in which participants were taking part in a new screening program, might have effectively selected out individuals who felt themselves to be at lower risk. Both of the US studies cited above used samples from community settings: Aiken et al. (1995) used the context of a community women's group, and Lipkus, Rimer, Lyna et al. (1996) assessed adult users of a community health centre. However, against this

interpretation is the fact that a UK population survey similar in age group to the present sample, but without any mention of screening, showed similar low levels of optimism for bowel cancer (Wardle, et al., 1999), suggesting that British pessimism rather than the selective recruitment of British pessimists is more likely to explain the findings.

Another hypothesis is that, in the UK, unusual access to preventive care and screening services has resulted in greater awareness of health risks. Against this view is the fact that bowel screening is not currently available in the UK and a study by McCaffery et al. (2003) of older British adults found that participants had not really thought about bowel cancer before. It seems therefore that knowledge of bowel cancer and bowel screening are low in the UK population and cannot explain why the UK respondents are less optimistic than the US respondents. The converse of this of course is that in the US bowel screening does exist and so people may feel more optimistic because they are being 'checked-out'.

Study 1 also examined the impact of varying the number of response options to comparative risk questions. Overall, the pattern of results for those given three response options was similar to those given five response options. The only slight difference that was apparent was that in the centres given five response options respondents gave a wider range of responses with both more optimistic and pessimistic judgments made than respondents given only 3-point scales. Further, in the centres given five response options there was slightly less missing data (4%) than in the three response options centres (6%)[10]. It is hard to judge whether these differences are meaningful given that there may be systematic differences in the two samples which have not been controlled for. There is some evidence to suggest that scales with more response options can better capture respondents beliefs. Diefenbach et al. (1993) examined the effectiveness of a variety of likelihood scales by asking participants how easy the scale was to use and how well the scale reflected their feelings. They found that a seven-point verbal category scale performed significantly better than a two-point, five-point, nine-point, eleven-point, twelve-point or hundred-point scale. The results for the five-point verbal category scale were similar, but slightly worse on all criteria. Diefenbach et al.'s finding of the superiority of

[10] This pattern of missing data was not seen for other variables suggesting that there was something about having 3 response options to the comparative risk question that made participants miss out the question more than when they were given 5 response options.

the seven-point scale is in contrast to previous work showing a five-point scale to have the greatest reliability and internal consistency (e.g. Jenkins & Taber, 1977; McKelvie, 1978). In terms of the present study, although the three-point scale showed almost the same pattern of result as the five-point scale, future studies may benefit from using a five-point or even seven-point response scale to reduce the number or participants judging their risk to be "the same" and reduce missing data.

The second aim of Study 1 was to examine the demographic and health-related correlates of perceived risk for bowel cancer in a large, population survey of older men and women. Univariate analyses showed that respondents who were male, older, and non-white, viewed their risk of bowel cancer as lower than their peers. In line with other work, having a family history, poorer health behaviours, more related (bowel) symptoms, poorer subjective health, and higher levels of anxiety were all also associated with higher perceived risk. Effects which were measured at more than two levels (e.g. family history) showed a 'dose-response' relationship.

The results from the multivariate analysis were broadly similar to the univariate analyses for gender, age, ethnicity, family history, bowel symptoms, subjective health, health behaviours and anxiety, indicating that these factors contributed independently to perceived risk.

It was interesting to find that being male and older were both associated with lower perceived risk, because these two factors have consistently been linked to higher risk of bowel cancer, at least in the UK (Quinn et al., 2001), so the comparative optimism bias was opposite to the true risk. It is perhaps understandable that men may feel less at risk for bowel cancer than women because although men have a shorter life expectancy, they tend to experience less ill health during their lives (Nathanson, 1975; 1977). The associations showing older age to be related to more comparative optimism may be an example of Weinstein's (1982) 'absent/exempt' finding. This is the belief that if the problem has not yet appeared it is unlikely to appear now. Thus, the older age group may incorrectly perceive themselves to be at lower risk because they have reached their current age with no indication that they are likely to develop bowel cancer. These findings highlight the need for future risk communications to address any misperceptions surrounding age and gender.

Non-white respondents were substantially more comparatively optimistic in their bowel cancer risk judgments. It is possible that they could be relatively accurate in their view as African, Caribbean and South Asian migrants to England and Wales (the three groups representing the majority of immigrants to the UK) have been shown to have significantly lower risk of bowel cancer than white Britons (Barker & Baker, 1990; Grulich, Swerdlow, Head & Marmot, 1992; Swerdlow, Marmot, Grulich & Head, 1995). However, longer-term residence in the UK might raise bowel cancer risk compared with the country of origin. It will be interesting to see if subsequent generations have risks similar to the white UK population.

The association between socioeconomic deprivation and perceived risk was not particularly clear and of borderline significance. In the univariate analysis the individual deprivation score was significantly related to perceived risk but the effect disappeared in the multivariate analysis. Further analyses revealed that it was subjective health which caused individual deprivation to become non-significant, indicating a degree of association between the two predictor variables. This finding is not unexpected because poorer subjective health tends to be more prevalent in deprived groups (Bobak, Pikhart, Hertzman, Rose, & Marmot, 1998; Franks, Gold, & Fiscella, 2003) and associated with greater perceived risk.

Of the health-related correlates, family history, bowel symptoms and subjective health were the three factors showing the strongest associations with perceived risk, confirming studies that show these to be frequently cited as influences on personal risk judgments (Helzlsouer et al., 1994; Lipkus, Rimer, & Strigo, 1996; Weitzman et al., 2001). These findings are of some concern. The problem with individuals 'using' family history of bowel cancer to judge their own risk is that the genetic link for the vast majority of colorectal malignancies is limited (Lichtenstein et al., 2000), so while a strong family history might be a cause for greater vigilance, the absence of a FDR is no basis for complacency. The finding that bowel symptoms and subjective health strongly influence risk perception is also worrying given that the pathogenesis of bowel cancer is often asymptomatic until an advanced stage (Department of Health, 2000), so lack of symptoms and feeling well should not lead individuals to believe themselves to be at low risk. Risk communications about bowel

cancer therefore need to tackle misunderstandings both of the familial link and the pathogenesis of bowel cancer.

One reassuring finding is that smokers and non-exercisers appear to recognize their increased risk of developing bowel cancer. Both groups perceived their risk to be higher than non-smokers and exercisers, in line with previous work (Vernon et al., 1993; Helzlsouer et al., 1994; Lipkus, Rimer, Lyna et al., 1996; Lipkus, Rimer, & Strigo, 1996; Skinner et al., 1998; Vernon et al., 2001). This reflects a relative accuracy in their judgments because smoking and inactivity have been associated with increased risk of bowel cancer (Colditz et al., 2000). However, it is unlikely that most people are aware of this specific link, so the association could represent a confound with another, unmeasured variable. Indeed Study 4, which takes a qualitative approach to examining the factors people take into account when making their bowel cancer risk judgements, found that very few people even mentioned smoking or exercise in talking about their chances of developing bowel cancer.

As expected, there was a 'dose-response' relationship between perceived risk and interest in bowel screening such that those who viewed their risk as lower than average were less interested in screening while those who perceived their risk as the same or higher than average were considerably more interested in attending screening. This finding replicates the relationship found in the pilot centres of the UK FS Trial (Wardle et al., 2000).

There are limitations to this study that need to be considered in interpreting the results. It is part of a larger scale project on bowel cancer screening, which might limit or bias participation. Participation rates at the survey stage were moderate (61% response rate; similar to other primary care surveys e.g. Walsh, (1994), so there is a substantial group whose risk estimates are unknown. Comparative optimism levels were similar to those found in a parallel survey not raising the issue of screening discussed earlier (Wardle et al., 1999), so the screening context does not seem likely to significantly bias the results. The measures of smoking and exercise were simple one-item questions to reduce participant burden, but single items have lower reliability and therefore reduce the chance of getting a significant result. However, the huge sample size means that a negative result is likely to be a real negative and not just a failure to detect a small positive associations. A possible

limitation of the family history measure is that some investigators (e.g. Vernon et al., 2001) have also examined whether relatives were diagnosed with polyps which may be indicative of increased familial risk. This type of question may be appropriate for countries where bowel screening is widely available, but because this is currently not the case in the UK it seems unlikely that most people would know what a polyp is. This may be an important question to address in future research when screening is introduced and public knowledge of polyp status increases. Finally, the study is also limited in that it is cross-sectional in design and so cause and effect cannot be determined. It is possible that the inclusion of questions on family history and symptoms may have alerted participants to their possible effect on bowel cancer risk, as question order has been shown to affect people's responses to survey items (Tourangeau, Rips, & Rasinski, 2000), but this is minimized by the fact that in the questionnaire the comparative risk question came before any questions on family history and bowels symptoms. Further, we know from a separate sample of UK adults that many of the participants had never really thought about bowel cancer before, so it is unlikely that their perceptions of cancer affected the other variables (McCaffery et al., 2003).

The present study is unique in examining perceptions of risk for bowel cancer in a large, population sample of both men and women. The sample showed the predicted optimistic bias, although the level of optimism was remarkably lower than US-based studies have found. The study is also the first of its kind to explore the correlates of perceived risk for bowel cancer in a large population sample and to take a multivariate approach for a broad range of demographic and health-related factors. The results indicate that there are a number of different factors which tend to promote lower levels of perceived risk. Being male and older were each associated with lower perceived risk. Misperceptions such as these should be addressed in public health education. Lack of a family history of disease and fewer physical symptoms are factors which might logically decrease perceived risk, but in the context of population-based pre-symptomatic screening may serve as barriers to preventive health behaviours. Being less anxious and having a healthier lifestyle are, as expected, associated with lower perceived risk but are also likely to be related to (other) beneficial health behaviours such as screening.

In practical terms, if a bowel cancer screening program is to be effective then as many of the population as possible need to be sufficiently motivated to participate. Perceived risk is the key motivating factor in almost all models of preventive behaviour. The present study has identified several correlates of perceived risk and in so doing has highlighted factors which we may be able to address in public health education to increase screening participation.

It is clear that important associates of perceived bowel cancer risk have been identified, but as noted above only a limited number of associations could be assessed within this dataset. It is possible that other factors may be influencing people's risk judgements and this deserves further consideration. It would also be interesting to explore in more depth some of the misperceptions surrounding age, gender, and the pathogenesis of bowel cancer. The present study found that a family history was associated with greater perceived risk but it is not entirely clear whether this was due to beliefs about genetic inheritance or shared lifestyle or was the result of the availability bias. These issues will be addressed in Studies 4 and 5.

# CHAPTER 5

## Study 2: Examining the relationship between subjective and objective risk of bowel cancer[11]

### 5.1. Introduction

The aim of Study 2 was to examine the relationship between perceived and actual risk of bowel cancer. Study 1 found that certain subgroups e.g. men and older adults showed a tendency to be comparatively optimistic about their perceived susceptibility to bowel cancer, yet for some risk factors, notably smoking and exercise, participants were relatively accurate in their risk judgements and recognised that their habits could put them at higher risk. It is therefore possible that there may be some correspondence between perceived and actual risk of bowel cancer.

Previous work in the cancer literature has attempted to assess the accuracy of personal risk appraisals by comparing perceived risk with results from risk algorithms such as the Gail Model for breast cancer (e.g. Lipkus, Rimer & Strigo, 1996; Woloshin et al., 1999; Weinstein et al., 2004). Small but significant effects have been found, with Lipkus, Rimer and Strigo (1996) reporting an association of r=0.21 between perceived breast cancer risk and Gail Model score, and Weinstein et al., (2004) finding an association of r=0.22 between perceived risk and a risk algorithm for bowel cancer. Kreuter and Strecher (1995) found that people who were more comparatively optimistic tended to be in the actuarially lower risk category for heart disease, stroke, cancer or having a motor vehicle crash, as assessed by health risk appraisal algorithms. No study in the cancer field has compared perceived risk with a clinical endpoint. Determining whether people have accurate

[11] A version of this paper was published in *Cancer, Causes and Control*, **15**, 21-25, 2004, and is included in Appendix 3.

perceptions of their risk will establish whether people need to be better informed about their risk status to encourage more cancer preventive behaviour.

The present study used findings from FS screening as a proxy clinical endpoint against which to evaluate the accuracy of perceptions of risk of bowel cancer. FS screening generates a range of screening outcomes from negative (no polyps), through lower risk polyps (hyperplastic polyps), higher risk adenomatous polyps, and ultimately cancers (Dave, Hui, Kroenke, & Imperiale, 2003). The scientific advantage of doing this study in the UK was that colorectal screening is not yet included in the national screening program and people who had had a recent bowel examination were excluded from the Trial. None of the participants had therefore been exposed to prior screening, which could have confounded the measure of perceived risk. Pre-screening assessments of perceptions of risk, were collected from a large sample of older adults, and for the present analyses, these were linked with findings at screening. Data described in Study 1 showed that 16% of the population rated themselves as 'lower than average risk' compared with 8% as 'higher than average', and that comparative optimism was associated with lower interest in attending screening.

### *5.1.1 Hypotheses*

The hypotheses for Study 2 are as follows:

1. Known characteristics such as gender, age, family history, smoking, and exercise will be significantly related to screening outcome.
2. Participants will show an optimistic bias in perceptions of risk for bowel cancer (data here are from those who attended screening compared with data from the baseline survey described in Study 1).
3. Comparative optimism about developing bowel cancer will be associated with being at lower risk as determined by findings at FS screening.

## 5.2. Methods

### *5.2.1. Design, participants and procedures*

The design of this study was prospective, with perceived risk measured prior to participants being invited to attend for screening. None of the participants had been screened before since screening is not otherwise available in the UK, and those who had recently had their bowel examined for diagnostic purposes were excluded from the Trial (UK Flexible Sigmoidoscopy Screening Trial Investigators, 2002).

Participants (N=15,922) were men and women aged 55-64 years, registered with General Practitioners (GP). They were a subset of participants in the UK FS Trial (Atkin et al., 2001; UK Flexible Sigmoidoscopy Screening Trial Investigators, 2002) who had both been randomized to the screening arm and been randomly selected to be sent a baseline questionnaire before screening invitations were sent out. The questionnaire was the same eight page instrument described in Study 1, although there were slight variations in some of the questions asked between the centres. Participants came from 12 of the Trial centres[12] (Birmingham, Glasgow, Leicester, Leeds, Manchester, Newcastle, Newport, Oxford, Portsmouth, Harrow, Swansea and Welwyn Garden City).

67% of potential participants responded "yes, definitely" or "yes, probably" to the screening interest question and were randomised to screening or control arms in the ratio 1:2. People living at the same address were randomised to the same arm of the Trial. Those in the screening group were sent an invitation for screening with a specified appointment about five weeks in advance, and were asked to telephone to confirm, change, or cancel their appointment. Those who confirmed their appointment were mailed a bowel preparation (a single phosphate enema) to self administer prior to attendance.

Screening was performed in endoscopy units by experienced specialist gastroenterologists. Endoscopists were encouraged to remove all small polyps during flexible sigmoidoscopy. Polyps smaller than 3 mm in diameter in the distal 5 cm of the rectum were ignored at the

[12] All 14 centres were not used because psychological questionnaires were not sent to the Norwich centre and Liverpool was excluded.

discretion of the endoscopist if they were judged on endoscopic appearance to be hyperplastic. Referral for colonoscopy was required for participants found to have polyps meeting high-risk criteria (for full details see UK Flexible Sigmoidoscopy Screening Trial Investigators, 2002).

Ethics approval was obtained locally at each of the centres.

### *5.2.2. Materials*

*Perceived risk.* The perceived risk/comparative optimism item asked: "Compared with other men and women of your age, do you think your chances of getting bowel cancer are: lower; about the same; higher" based on Weinstein (1987). Responses were scored by allocating -1 for "lower", 0 for "about the same" and +1 for "higher".

*Demographic characteristics.* Age and gender were known from the health authority records. Additional simple questions were used to assess ethnicity, "Which of these best describes your ethnic background? White; Black; Asian; Other; do not wish to answer", and marital status, "What is your marital status? Married/living as married; Divorced; Separated; Widowed; Single".

Postcode data were used to obtain Townsend scores, as described in Study 1. The Townsend Index provided an external validity check to the individual deprivation score and also allowed comparisons to be made between responders and non-responders.

In addition, an individual marker of socioeconomic deprivation was measured because Townsend Material Deprivation Index scores were not available for participants from Glasgow. This is because Scotland uses a different measure of neighbourhood-level deprivation, known as the Carstairs Score (based on unemployment, overcrowding, car ownership and low social class, Carstairs & Morris, 1991). Townsend scores (with Glasgow excluded) were still considered to allow comparison between the socioeconomic profile of the sample and the national average. Individual socio-economic deprivation was measured by a score composed of three demographic items. "Does your household have a car?" ("yes; no"); "Do you own or rent your home?" ("own it/buying it; rent it; other"); and

"Do you have any educational qualifications?" ("yes; no"). One 'deprivation point' was given for each of the following; the household not owning a car; not owning the home and having no educational qualifications. This resulted in the individual deprivation score ranging from 0-3 with 0 representing the most affluent group and 3 the most deprived group.

*Risk exposures for bowel cancer.* The relationship between risk exposures and screening outcome was also examined in the present study to determine if simple measures of self-reported risk exposure were associated with screening outcome. Colditz et al. (2000) proposed the Harvard Cancer Risk Index to provide a broad classification of cancer risk, for various cancers, based on group consensus among researchers at the Harvard Medical School and Harvard School of Public Health. The UK FS Trial measured some of the components of the Risk Index in the questionnaires. These include family history, smoking, exercise and bowel symptoms.

Family history of bowel cancer in FDRs was assessed with the question, "Have any members of your family (BLOOD relatives, not relatives by marriage) had bowel cancer?" Options were mother; father; son(s), daughter(s), sister(s), brother(s) with participants asked to indicate "yes; no; don't know" for each relative. For each participant the total number of relatives with bowel cancer was calculated and then coded into categories of none, one, and two or more.

Health behaviours were assessed with two single items which asked if participants smoked or took regular exercise. The smoking question asked, "Do you smoke cigarettes at all nowadays?" (Health Survey for England, 1996) and the exercise question asked, "Do you take regular exercise each week?". Response options were "yes" or "no". In three of the centres (Manchester, Newcastle and Newport) questions on smoking and exercise were not included in the questionnaires, but smoking information was available for these centres from the 'Pre-Screening Medical Form' which participants completed at the hospital immediately before the FS procedure. The smoking question asked, "Were you ever a regular smoker?" Response options were, "yes" or "no."

Bowel symptoms over the past three months were assessed with a list of 7 symptoms (constipation, haemorrhoids, diarrhoea, wind, pains in abdomen, incontinence, blood in stools). Symptom frequency was rated as "no; occasionally; frequently." A total symptoms score was calculated by totaling the number of symptoms that were experienced occasionally or frequently.

*Objective risk.* Objective risk was based on findings at screening. In a systematic review of the literature Dave et al. (2003) concluded that persons with distal hyperplastic polyps have a risk of proximal neoplasia that is intermediate between those persons with no distal polyps and those with distal adenomas. Therefore, the screening results were graded in order of severity; that is 'no abnormalities' represents the lowest level of risk followed by those with 'hyperplastic polyp' which represents an intermediate level of risk, 'adenoma' represents increased risk of bowel cancer and the highest grading is obviously 'cancer'. These outcome categories do not directly map the perceived risk categories but are approximations of true risk.

### *5.2.3. Analysis of results*

SPSS (Version 10.1) was used to analyse all data. One-Sample t-tests were employed to examine whether the mean Townsend Index score for respondents was significantly different from 0 which represents the national average, and to detect an optimistic bias in perceived risk with a significant deviation from the midpoint 0 (the score representing average risk)[13].

Linear trends in proportions across screening outcome groups were assessed with SPSS linear-by-linear Chi square tests (a measure of linear associations between the row and column variables in a cross-tabulation). Linear trends were examined for risk exposures, demographic characteristics and perceived risk in relation to screening outcome. Spearman's rho was calculated to assess the association between perceived and actual risk.

[13] The limitations of using this statistical method on an ordinal variable are acknowledged in Study 1.

Multiple regression was considered not to be appropriate as the dependent variable (screening outcome) had only 4 categories and multiple regression is not recommended if the dependent variable has fewer than 5 categories (Cohen et al., 2003). Similarly, collapsing the dependent variable into a dichotomous variable for logistic regression would result in a loss of information. Ordinal logistic regression is an extension of logistic regression to the analysis of ordered category dependent variables. Categories, organised in ascending order, are assumed to reflect an underlying continuum, and movement from one category to the next indicates that a threshold of the continuum has been crossed. Differences between thresholds are not necessarily equally spaced. Ordinal logistic regression models the odds of transition across thresholds, given values on the predictor variables. That is, it is assumed that the predictors have the same impact on crossing all the thresholds (Cohen et al., 2003). In ordinal regression one value (typically the first or last) is designated as the reference category and the probability of membership in other categories is compared to the probability of membership in the reference category (Menard, 2002). Univariate and multivariate ordinal regressions were used to assess the relationship between actual risk, comparative risk, demographic factors and risk exposures.

Pseudo R squared (McFadden) for logistic ordinal regression was used to assess how much of the variance in screening outcome could be explained by the predictor variables available. SPSS provides three estimates of Pseudo R-squared in ordinal regression; Cox and Snell; Nagelkerke; and McFadden. Pseudo R-squared offers an approximation for R squared but is not as widely useful as the regression R squared (Agresti, 1990). Because there is a degree of uncertainty about the usefulness of Pseudo R-square estimates, I opted to report the McFadden value as it provides the most conservative estimate.

## 5.3. Results

### *5.3.1. Respondents*

10,551 of those who had a) been randomized to screening and b) completed a questionnaire prior to their screening invitation, attended screening and therefore had a clinical endpoint. The mean age of the 10,551 participants was 60 years (sd=2.9) with almost equal numbers

of men (49.7%) and women (50.3%). 97% of the sample were white and 80% were married. Townsend scores were available for 9272 participants, but not available for the 1174 participants in the Glasgow centre. The remainder of missing Townsend scores amounted to 0.01% (n=105) of the sample and were missing for a variety of reasons including; inaccurate health authority records; new houses for whom Townsend Index scores had not yet been calculated. Participants had significantly lower Townsend Index scores ($M$=-1.14, $SD$=2.90) than the national average for England and Wales ($t$(9271)=-37.74, p<0.001), indicating that they were a less deprived group.

### *5.3.2. Comparative optimism*

Overall the sample showed the expected optimism bias at pre-screening with a One-sample t-test detecting a significant deviation from the midpoint (0) ($M$=-0.09 $SD$=0.49), $t$(9058)=-17.42; p<0.001. 17% perceived their risk of developing bowel cancer as lower than others (henceforth called bowel cancer optimists) and only 8% perceived their risk as higher than others (bowel cancer pessimists).

### *5.3.3. Screening outcome*

74% of participants had negative findings at screening, 12% had lower risk findings (e.g. hyperplastic polyps), 13% had adenomas putting them at higher risk of bowel cancer, and 0.4% had a cancer, see Table 5.1.

**Table 5.1: Screening outcome**

| | n (N=10551) | % |
|---|---|---|
| No abnormalities | 7849 | 74.4 |
| Hyperplastic polyp | 1320 | 12.5 |
| Adenoma | 1345 | 12.7 |
| Cancer | 37 | 0.4 |

*5.3.4. Screening outcome and risk exposures*[14]

As predicted, those with a family history of bowel cancer were almost twice as likely to be found to have an adenoma (24%) than those without a family history (12%). Similarly, 75% of respondents with no family history of bowel cancer were found to have no abnormalities compared with 71% of respondents with 2 or more first degree relatives, see Table 5.2.

Those with bowel symptoms were no more likely to be in a higher risk category (12%) than those without bowel symptoms (13%). In fact it is well known that bowel cancer is asymptomatic until an advanced stage but it was still surprising to see that those with more bowel symptoms were actually more likely to have a negative screening compared to those with only 0 or 1 bowel symptom. 76% of those with 4 or more symptoms had no abnormalities compared with 74% who reported 0 or 1 bowel symptom, see Table 5.2.

As expected, significantly more smokers (17%) had high risk screening outcomes than non-smokers (11%). Smokers were also less likely to have no abnormalities (62%) compared to non-smokers (78%).

Surprisingly, exercise did not show a significant relationship with screening outcome. 75% of exercisers had no abnormalities found compared with 73% of non-exercisers, however this difference was not significant.

[14] It is acknowledged that because the outcome category 'cancer' has relatively few cases, in certain instances the linear-by-linear chi-square test violates the assumptions of the chi square test by having fewer than 5 counts in a cell. This occurs for those with 2 or more FDR who were found to have cancer. I re-ran the analyses combining 'cancer' with 'adenoma' and got almost identical results. I have left 'cancer' as a separate category as I believe it will be of interest to the reader, but acknowledge the problems with doing this.

**Table 5.2: Risk exposures/health related factors in relation to screening outcome (univariate analyses)**

| | Screening outcome | | | | Significance |
|---|---|---|---|---|---|
| | No abnormalities (n=7849) | Hyperplastic polyp (n=1320) | Adenoma (n=1345) | Cancer (n=37) | |
| **Risk exposures %** | | | | | |
| Family history | | | | | |
| 0 (n=9206) | 74.7 | 12.5 | 12.4 | 0.3 | |
| 1 (n=1011) | 70.1 | 13.2 | 16.2 | 0.5 | |
| 2+ (n=55) | 70.9 | 5.5 | 23.6 | 0 | $\chi^2(1, 10272)=15.3$, $p<0.001$ |
| Bowel symptoms | | | | | |
| 0-1 (n=5285) | 73.5 | 12.7 | 13.4 | 0.4 | |
| 2-3 (n=3563) | 74.7 | 12.6 | 12.3 | 0.3 | |
| 4+ (n=1703) | 76.5 | 11.7 | 11.5 | 0.3 | $\chi^2(1, 10551)=7.0$, $p=0.008$ |
| Smoke | | | | | |
| Yes (n=2495) | 61.9 | 20.4 | 17.2 | 0.4 | |
| No (n=7801) | 78.3 | 10.1 | 11.3 | 0.3 | $\chi^2(1, 10296)=186.0$, $p<0.001$ |
| Exercise | | | | | |
| Yes (n=5214) | 75.2 | 12.0 | 12.3 | 0.4 | |
| No (n=2646) | 73.2 | 13.3 | 13.2 | 0.3 | $\chi^2(1, 7860)=2.49$, $p=0.115$ |

### *5.3.5. Screening outcome and demographic factors*[15]

Men were more likely than women to have a positive screening result (32% vs. 19%) and they were almost twice as likely to have an adenoma, see Table 5.3. There were no differences in screening outcome by age group, or marital status. White participants were significantly more likely than non-whites to have a higher risk outcome, see Table 5.3. Socioeconomic deprivation showed a slight association with having higher risk findings (31%) compared with the more affluent participants (25%). Strikingly, the most deprived

[15] It is again acknowledged that because the outcome category 'cancer' has relatively few cases, in certain instances the linear-by-linear chi-square test violates the assumptions of the chi square test by having fewer than 5 counts in a cell. This occurs for those in the two most deprived quartiles for those found to have cancer. I re-ran the analyses combining 'cancer' with 'adenoma' and got almost identical results. I have left 'cancer' as a separate category as I believe it will be of interest to the reader, but acknowledge the problems with doing this.

group had twice as many cancers found (0.8%) as the most affluent group (0.4%), however the SES difference was not statistically significant.

**Table 5.3: Demographic characteristics and perceived risk in relation to screening outcome (univariate analyses)**

| | Screening outcome | | | | |
|---|---|---|---|---|---|
| | No abnormalities (n=7849) | Hyperplastic polyp (n=1320) | Adenoma (n=1345) | Cancer (n=37) | Significance of difference |
| Gender % | | | | | |
| Female (n=5304) | 80.8 | 10.2 | 8.8 | 0.2 | |
| Male (n=5247) | 67.9 | 14.8 | 16.7 | 0.5 | $\chi^2(3, 10551)=242.8$, $p<0.001$ |
| Age % | | | | | |
| 55-59 (n=5298) | 74.9 | 12.3 | 12.6 | 0.2 | |
| 60-64 (n=5221) | 73.9 | 12.7 | 12.9 | 0.5 | $\chi^2(1, 10519)=2.1$, $p=0.149$ |
| Marital status % | | | | | |
| Married (n=7300) | 74.8 | 12.3 | 12.5 | 0.4 | |
| Not married (n=1837) | 74.1 | 11.9 | 13.6 | 0.4 | $\chi^2(1, 9137)=1.0$, $p=0.317$ |
| Ethnic group % | | | | | |
| White (n=8874) | 74.4 | 12.4 | 12.9 | 0.4 | |
| Non-white (n=182) | 87.9 | 4.9 | 7.1 | 0 | $\chi^2(1,9056)=13.9$, $p<0.001$ |
| Socioeconomic deprivation % | | | | | |
| 0 (n=3716) (affluent) | 75.4 | 11.5 | 12.6 | 0.4 | |
| 1 (n=3454) | 74.2 | 12.8 | 12.7 | 0.3 | |
| 2 (n=1195) | 75.2 | 11.0 | 13.7 | 0.1 | |
| 3 (n=380) (deprived) | 68.9 | 16.1 | 14.2 | 0.8 | $\chi^2(1, 8745)=2.6$, $p=0.110$ |

### *5.3.6. Screening outcome and perceived risk*[16]

A modest relationship was found between risk judgments and actual risk, Spearman's rho=0.030, p=0.004. 77% of bowel cancer optimists had no abnormalities detected compared to 71% of bowel cancer pessimists (see Table 5.4). 14% of bowel cancer pessimists were found to have an adenoma compared to only 11% of bowel cancer optimists.

**Table 5.4: Perceived risk in relation to screening outcome (univariate analysis)**

| | Screening outcome | | | | |
|---|---|---|---|---|---|
| | No abnormalities (n=7849) | Hyperplastic polyp (n=1320) | Adenoma (n=1345) | Cancer (n=37) | Significance |
| Perceived risk % | | | | | |
| Lower (n=1529) (optimists) | 76.8 | 11.8 | 11.2 | 0.1 | |
| The same (n=6813) | 74.5 | 12.1 | 13.0 | 0.4 | |
| Higher (n=717) (pessimists) | 71.1 | 14.6 | 13.7 | 0.6 | $\chi^2(1,9059)=8.5$ p=0.004 |

### *5.3.7. Ordinal regression*[17]

Univariate ordinal logistic regressions were carried out to provide direct comparisons with the multivariate analysis. Only those variables found to be significantly related to screening outcome in the SPSS linear-by-linear Chi-square tests were included in the ordinal regression. Univariate ordinal regressions showed that being female was associated with a decreased risk of developing bowel cancer compared to men, see Table 5.5 columns 1 and 2. Being white was related to greater risk of developing bowel cancer compared to being non-white. Having a family history of bowel cancer was not significantly related to

[16] It is acknowledged that because the outcome category 'cancer' has relatively few cases, in certain instances the linear-by-linear chi-square test violates the assumptions of the chi square test by having fewer than 5 counts in a cell. This occurs for bowel cancer optimists and bowel cancer pessimists found to have cancer. I re-ran the analyses combining 'cancer' with 'adenoma' and got almost identical results. I have left 'cancer' as a separate category as I believe it will be of interest to the reader, but acknowledge the problems with doing this.

[17] Re-running the univariate and multivariate ordinal regressions combining the 'cancer' category with the 'adenoma' category made no difference to the pattern of results.

screening outcome using univariate ordinal regression. Having fewer bowel symptoms was related to higher risk of developing bowel cancer, although this result was only just significant. Smoking was strongly related to higher risk screening outcomes. Being a bowel cancer optimist was associated with a decreased risk of developing bowel cancer.

A multivariate ordinal logistic regression was performed to assess the independent contribution of perceived risk while controlling for each of the other factors. The multivariate ordinal regression showed that being white independently predicted greater risk while being female predicted lower risk of developing bowel cancer, see Table 5.5 columns 3 and 4. Having a family history of bowel cancer and having bowel symptoms did not independently predict screening outcome. Smoking independently predicted greater risk of developing bowel cancer. In the multivariate analyses bowel cancer optimists were at a decreased risk of developing bowel cancer as were those who rated their risk as "the same", in a dose-response relationship, however the relationship was no longer significant.

To assess the contribution of perceived risk on screening outcome, in addition to the other predictor variables, Pseudo $R^2$s were calculated for the two models. For the first model (including predictors: gender, ethnicity, family history, bowel symptoms and smoking) Pseudo $R^2$ (McFadden) was 0.032. When perceived risk was added into this model Pseudo $R^2$ did not change and remained 0.032. This shows that perceived risk did not add in any way to explaining the variance in screening outcome. Pseudo $R^2$ of 0.03 suggests that only 3% of the variance in screening outcome was explained by the variables available. This is surprising given that gender, ethnicity and smoking appeared to have a large impact on screening outcome based on the odds ratios presented in Table 5.5, but illustrates the fact that different ways of presenting results, greatly affect their apparent impact.

**Table 5.5: Univariate and multivariate ordinal regressions of the predictors of FS screening outcome (No abnormalities/hyperplastic polyp/adenoma/cancer)**

| | Univariate odds ratios of screening outcome | Univariate significance | Multivariate odds ratios of screening outcome | Multivariate significance |
|---|---|---|---|---|
| Gender | | | | |
| Female | 0.50 [0.46, 0.54] | p<0.001 | 0.48 [0.43, 0.53] | p<0.001 |
| Male | 1.00 | | 1.00 | |
| Ethnicity | | | | |
| White | 2.47 [1.58, 3.85] | p<0.001 | 3.07 [1.85, 5.11] | p<0.001 |
| Non white | 1.00 | | 1.00 | |
| Family history | | | | |
| 0 | 0.73 [0.42, 1.28] | p=0.276 | 0.77 [.42, 1.43] | p=0.409 |
| 1 | 0.94 [0.53, 1.66] | p=0.824 | 0.96 [.52, 1.80] | p=0.911 |
| 2+ | 1.00 | | 1.00 | |
| Bowel symptoms | | | | |
| 0-1 (n=5285) | 1.18 [1.04, 1.34] | p=0.011 | 1.04 [.91, 1.20] | p=0.537 |
| 2-3 (n=3563) | 1.10 [0.96, 1.26] | p=0.157 | 1.08 [.94, 1.24] | p=0.281 |
| 4+ (n=1703) | 1.00 | | 1.00 | |
| Smoke | | | | |
| Yes | 2.08 [1.89, 2.29] | p<0.001 | 1.96 [1.75, 2.19] | p<0.001 |
| No | 1.00 | | 1.00 | |
| Perceived risk | | | | |
| Lower (optimists) | .75 [0.61, 0.91] | p=0.004 | 0.81 [0.65, 1.01] | p=0.057 |
| The same | .86 [0.72, 1.01] | p=0.071 | 0.90 [0.75, 1.09] | p=0.294 |
| Higher (pessimists) | 1.00 | | 1.00 | |

## 5.4. Discussion

The aim of this study was to see whether perceiving the risk of developing bowel cancer as lower than average – otherwise known as comparative optimism - was related to being actually at decreased risk. A unique aspect of the study was that actual risk was determined by findings at FS screening, providing a 'hard' outcome measure. In line with previous studies using algorithmic estimates of actual risk (Lipkus et al, 1996; Woloshin et al., 1999; Weinstein et al., 2004), a modest but significant relationship between perceived and actual risk was found in univariate analyses. Those who perceived their risk of developing bowel cancer to be lower were very slightly more likely to be in the low risk outcome group, while those who perceived their risk to be higher were very slightly more likely to be in the high risk outcome group. The findings are in line with the broader body of work showing that people's self-rated health is a strong predictor of future morbidity and mortality (Kaplan & Camacho, 1983; Idler & Benyamini, 1997). When a multivariate ordinal logistic regression was performed controlling for the other factors, perceived risk showed the same dose-response pattern but the result was no longer significant. This suggests that perceived risk was not independently contributing to the prediction of screening outcome beyond that explained by gender, ethnicity, and smoking.

Being a smoker was the only risk exposure consistently related to screening outcome in both univariate and multivariate analyses, with smokers being at higher risk. Surprisingly, exercise was not significantly related to outcome which is in contrast to substantial evidence showing regular exercise to be a protective factor against bowel cancer (Potter, Slattery, Bostick, & Gapstur, 1993; Colditz et al., 2000; Slattery & Potter, 2002). It is likely that this unexpected finding is due to the relatively insensitive measure of exercise used in the UK FS Trial ("Do you take regular exercise?" with response options "yes" or "no") which may not have adequately differentiated between exercisers and non-exercisers. For example people may indicate that they take regular exercise but it may not be enough to be protective e.g. 5 times for 30 minutes each week (Department of Health, 2004).

Having a family history of bowel cancer was significantly related to higher risk screening outcome when analysed using linear-by-linear Chi Square, but was found to be non-significant using univariate and multivariate ordinal logistic regression. This finding

concurs with the conclusions from Study 1 that individuals should not be overly dependent on their family history when judging their personal risk because in around 85% of cases of bowel cancer there is not a strong genetic link (Slattery et al., 2003).

The relationship between bowel symptoms and outcome was slightly unexpected in the univariate analyses with those reporting more bowel symptoms having lower risk findings. The epidemiological evidence indicates that conditions of the bowel such as chronic ulcerative colitis and Crohn's disease are associated with increased risk for bowel cancer (Colditz et al., 2000; Smith et al., 2001), but there is little evidence to suggest common bowel symptoms such as constipation, haemorrhoids, diarrhoea, wind, pains in the abdomen, incontinence, and blood in stools are related to increased risk of bowel cancer. It is perhaps not surprising that these symptoms were not associated with higher risk screening outcome, but why the univariate analyses showed that having more bowel symptoms was associated with lower risk remains something of a mystery. Levels of bowel symptoms were not independent predictors of screening outcome in the multivariate analysis. The findings on bowel symptoms are in line with the conclusions of Study 1 that respondents should not be overly reliant on bowel symptoms in judging their risk as being asymptomatic does not mean one is at lower risk.

As expected, and in line with the results from Study 1, respondents were, on average, optimistic about bowel cancer risk. Again, however, the number of respondents judging their risk to be lower than average was considerably less than studies in the US have found.

Being male and white (vs. non white) were both associated with higher risk as predicted from epidemiological findings (Quinn et al., 2001; Barker & Barker, 1990; Grulich, Serdlow, Head, & Marmot, 1992; Swerdlow, Marmot, Grulich, & Head, 1995). Age did not show a significant relationship with screening outcome despite increasing age being an established risk factor for bowel cancer (Quinn et al., 2001). It is possible that the current sample had too limited a range in age (55-64 years) to show any significant effects. Given that currently in the UK the relationship between SES and bowel cancer is flat (Quinn et al., 2001), it was not surprising to see no relationship between individual level socioeconomic deprivation and screening outcome.

It was surprising that the total amount of variance explained in screening outcome amounted to only 3%. From examining the odds in Table 5.5 it seemed that gender, ethnicity and smoking were having a large impact on screening outcome, yet the results of the Pseudo $R^2$ suggest their contribution was minimal.

The present study has some strengths, notably the large sample size and the proxy measure of clinical outcome. It also has limitations. The design of the study (i.e. the two-stage recruitment) meant it was possible that we had identified a more accurate group of optimists than exists in the population as a whole. Despite believing that they were at lower than average risk of developing bowel cancer, the optimists in the present sample were motivated enough to take active steps to reduce their risk further by attending FS screening. The group who should be of greater concern are optimists who are unwilling to engage in precautionary health behaviour. In the UK FS pilot study, people who believed their risk to be lower than average were much less interested in FS screening (26% not interested) compared with those who felt at higher than average risk (2%) (Wardle et al., 2000). It is possible that this group represents the 'unrealistic' optimists. This group of 'unrealistic' optimists could have a health advantage similar to the optimists taking part in this study, but this seems unlikely if their reluctance to take part in FS screening is representative of their attitude to precautionary health behaviour in general. The differentiation between 'unrealistic' optimists and 'realistic' optimists fits with Armor and Taylor's (1998) hypothesis about optimistic beliefs being either 'passive' or 'active'. 'Active' optimists will take steps to reduce their risk and so maintain their optimism (i.e. the bowel cancer optimists who attended screening in the present study) while 'passive' optimists are overly optimistic without considering relevant risk behaviours that may influence susceptibility. Armor and Taylor note that the two conceptualisations will have opposing consequences for self-regulation. 'Passive' optimists will not take preventative action because they believe they are not at risk while 'active' optimists believe they are free from risk because they have taken (or will take) the requisite preventative actions. Schwarzer (1994) also distinguishes between different types of optimists but terms them 'defensive' optimists and 'functional' optimists. Defensive optimists display similar characteristics to the 'passive' and 'unrealistic' optimists described above whereas the functional optimists represent the adaptive, 'active' type who take steps to reduce their risk. Wallston (1994) similarly discriminates between 'cockeyed' optimists and 'cautious'

optimists. Given that attempts to change optimistic biases have been largely unsuccessful (Weinstein & Klein, 1995) perhaps future work should try to harness this 'active' or 'functional' form of optimism by promoting the practice of behaviours that make optimism more warranted.

By comparing the mean Townsend score for the sample (with the Glasgow participants excluded from the analysis) with the mean Townsend score for England, the sample was shown to be significantly less socioeconocmically deprived than the national average which may limit the general conclusions that can be drawn from the study. However, given that Study 1 did not find a significant relationship between Townsend quartiles and perceived risk, and the present study found no significant effect of individual level deprivation on screening outcome it seems unlikely that having a sample with a more socioeconomically representative background would have changed the nature of the results. Furthermore, the Glasgow centre purposely over-sampled more deprived groups (McCaffery et al., 2002) and so it is possible that had participants from Glasgow been included in an analysis comparing the UK national average score for neighbourhood level deprivation, the sample may not have appeared as socioeconomically biased.

A stronger test of the hypothesis looking at the relationship between perceived and actual risk may have been to ask participants what they thought their chance was of finding a marker of higher risk such as a hyperplastic polyp or an adenoma, in addition to asking about cancer risk. However, given that most people (at least in the UK) have little knowledge of bowel cancer and its antecedents (McCaffery et al., 2003) the results would be difficult to interpret. Questions surrounding people's knowledge of polyp prevalence or awareness of the relationship between polyps and cancer may become more interesting once screening is introduced and risk markers are better publicised in the UK. This may be a possible avenue for future work.

One criticism of the study may be that the majority of participants exhibited neither optimism nor pessimism but rather viewed their risk as being similar to others (75%), and because finding a bowel abnormality is a relatively rare event, one should not expect a strong relationship because there is a lack of variance. I do not believe this is the appropriate interpretation of the results because 25% of participants gave a response to the

comparative risk question other than 'the same', and 26% of participants had an outcome other than 'no abnormalities'. This means there was sufficient variance in both perceived comparative risk and in screening outcome, and a very large sample size for the relationship to be reliably tested. Therefore, the relatively weak findings for accuracy is most likely due to participants being poor judges of their own risk and not because there was a lack of variance.

The modest association between subjective and objective risk in univariate analyses suggests that people are taking risk factors such as family history, smoking and exercise (and perhaps others) into account when making their risk judgments, as was indicated in Study 1. The small effect size may reflect both the participants' ability to take certain risk factors into account, and their apparent failure to acknowledge risk factors such as increasing age and being male in making their risk judgments. If the misperceptions identified in Study 1 could be addressed through improved risk communications then we may see a stronger association between perceived and actual risk.

The present study has shown that, as a group, optimists who attend for screening are at slightly lower risk of developing bowel cancer. However, the effect size is small. The practical utility of the present results comes from knowing that people are not particularly accurate in making personal risk judgments and so may not make the best decisions in terms of their health. For example 11% of comparative optimists were found to have an adenoma putting them at increased risk of developing bowel cancer. Health professionals should be made aware of this and encourage those who may not feel at risk to participate in cancer screening and other cancer preventive behaviours. 'Unrealistic' optimists who are less interested in screening may need particular encouragement from health professionals. Increasing people's ability to accurately perceive their risk of cancer may promote more appropriate cancer preventive behaviour.

This work could potentially be extended in the future. As the FS Trial is longitudinal and participants are to be followed up 10 years after randomisation, it will be possible to examine how perceptions of risk relate to morbidity and mortality over this period.

# CHAPTER 6

## Study 3: Determining how well demographic and health-related factors explain the variance in perceived risk for bowel cancer

### 6.1. Introduction

Weinstein (1984) asked people to rate their personal risk for a range of health and safety threats, and then asked them why they had estimated their risk in that way. Weinstein (1984) found that five factors appeared to be relevant; actions and behaviour patterns, heredity, physical/physiology, psychological attributes, and environmental factors. These five factors provide a useful framework for exploring the correlates of perceived risk. In Study 1, I examined the relationship between demographic, health-related and emotional factors, and perceived risk. An alternative way of analysing these data would be to assess the extent to which the five factors in combination 'explain' the variation in perceived risk. No study has, to my knowledge, assessed the five factors in this way. It should be noted that Weinstein did not propose the five factors as predictors in a model of comparative perceived risk, but noted that these five factors effectively categorized people's explanations for their risk judgements. However, given they are based on the reasons individuals give to justify their risk estimates, the present study will treat the five factors as a model to explain comparative perceived risk.

Existing studies have typically used one of two designs. They have either asked respondents the reason for their estimate in an open-ended fashion or they have related the level of comparative optimism/perceived risk to one or two of the factors. Several studies (Blalock et al., 1990; Aiken et al., 1995; Lek & Bishop, 1995; Lipkus, Rimer, Lyna et al, 1996; Lipkus, Rimer, & Strigo, 1996) using the former approach have evaluated Weinstein's scheme by coding responses into one of the five categories. Studies using the second approach have either looked at each predictor variable in isolation (e.g. Hay et al.,

2002) or have only assessed one or two of the five factors in multivariate analyses (Helzlsouer et al., 1994; Vernon et al., 2001).

Two studies have coded the reasons people give for their bowel cancer risk estimates (Blalock et al., 1990; Lipkus, Rimer, Lyna et al., 1996). In the Blalock et al. study, physiology, personal actions/behaviour patterns and heredity were the three most commonly mentioned reasons while environmental and psychological factors were rarely mentioned. In contrast, Lipkus, Rimer, Lyna et al., found that psychological factors were most frequently mentioned folllowed by heredity, personal actions and physiology with environmental factors rarely mentioned. It is surprising that psychological factors were mentioned so frequently in the Lipkus, Rimer, Lyna et al., study but not in the Blalock et al. study or in two studies on breast cancer (Aiken et al., 1995; Lipkus, Rimer & Strigo, 1996). The study by Lipkus, Rimer, Lyna et al. was based on predominantly low-income, African Americans and it is possible that as a group they are more likely to offer psychological explanations.

The present study takes a tangential approach to the framework as it seeks to determine if using each individual's position on each domain predicts their risk judgement. The study used exactly the same sample and data as in Study 1.

### *6.1.1 Hypothesis*

The hypotheses for the present study are:

1. The factors physical/physiology, heredity and personal actions will show the strongest assocations with perceived risk while the factors psychological and environment will be weakly related.
2. The majority of the variance in perceived risk for bowel cancer will be explained by the five Weinstein factors.

## 6.2. Methods

### *6.2.1. Design, participants and procedures*

The methods used in Study 2 are identical to those in Study 1 and so are not repeated here.

### *6.2.2. Operationalising Weinstein's (1984) five factors*

From the literature review it was clear that the five categories could be operationalised in a number of ways. Examples of the five factors taken from the two studies looking at the reasons people give for their comparative bowel cancer risk judgements are shown in Table 6.1.

**Table 6.1. Examples of the five Weinstein factors for bowel cancer**

| Author | Actions and behaviour patterns | Heredity | Physiology or physical attributes | Environment | Psychological attributes |
|---|---|---|---|---|---|
| Blalock, Devellis, Afifi, & Sandler (1990) | (Poor) diet. Try to eat properly | So much cancer in the family All family in real good health | Has burning in stomach Never had any problems | All the things they put in food Never had a job requiring strenuous work | Feel like I could get it Trust that I won't get it |
| Lipkus, Rimer, Lyna et al., (1996) | Diet, exercise, smoking | Family history | Stomach burning | All the things they put into food | Feel that I could get it. |

Using the UK FS Trial data, I was limited to the measures I had available to operationalise Weinstein's (1984) five factors. I initially selected the measures to operationalise the factors. Discussions with JW and AM, who are both very familiar with the UK FS Trial data, confirmed that these were the most appropriate measures to use. In each case the number of outcome categories was limited to 2 to 4 categories for better comparison across predictor variables. The factors were operationalised in the following manner:

*"Actions and behaviour patterns".* These were operationalised with two single items which asked if participants smoked or took regular exercise. The smoking question asked,

"Do you smoke cigarettes at all nowadays?" (Health Survey for England, 1996) and the exercise question asked, "Do you take regular exercise each week?". Response options were "yes" or "no".

*"Heredity"*. Family history of CRC was assessed with the question, "Have any members of your family (BLOOD relatives, not relatives by marriage) had bowel cancer?" Options were mother; father; son(s), daughter(s), sister(s), brother(s) with participants asked to indicate "yes; no; don't know" for each relative. These responses were coded into categories of none, one, and two or more.

*"Physiology or physical attributes"*. Bowel symptoms and subjective health were used to assess 'physiology'. Bowel symptoms over the past three months were assessed with a list of 7 symptoms (constipation, haemorrhoids, diarrhoea, wind, pains in abdomen, incontinence, blood in stools). Symptom frequency was rated as '"no; occasionally; frequently". A total symptoms score was calculated by totaling the number of symptoms that were experienced occasionally or frequently. As in Study 1 symptom frequency scores were divided into three groups for analyses (0,1; 2,3; 3+). Subjective health was assessed with the item, "Would you say that for someone of your age your own health in general is: excellent; good; fair; poor" (Health Survey for England, 1996).

*"Psychological attributes"*. State anxiety was recorded with the shortened, 6-item version of the Spielberger State Trait Anxiety Inventory (STAI; Spielberger, 1983; Marteau & Bekker, 1992). Respondents were asked to indicate on a four-point Likert type scale ranging from "not at all" to "very much" how they feel right now; calm, tense, upset, relaxed, content, worried. Internal reliability of the STAI was high with a Cronbach's $\alpha$=.83. As in Study 1, STAI scores were divided into tertiles for analysis.

*"Environment"*. Socioeconomic deprivation of the area of residence was employed as the measure of "environment" as a proxy for adverse material, social and economic conditions. More deprived postcodes are more likely to be exposed to environmental pollution due to their closer proximity to polluting factories than more affluent postcodes (King & Stedman, 2000). It was felt that the Townsend Index better captured the "environment" construct than the individual level deprivation measure. Postcode data were used to link participants'

area of residence to information from census enumeration districts (based on an average of around 460 residents) to index neighbourhood-level deprivation (the Townsend Material Deprivation Index; Townsend et al., 1988) using data from the 1991 census (Crown Copyright, 1991). The Townsend Index incorporates several indicators of socioeconomic deprivation including: unemployment, overcrowding, non-car ownership and non-home ownership. A Townsend score of zero represents the national average, negative values represent below-average levels of deprivation, and positive values represent higher than average deprivation.

### *6.2.3. Analysis of results*

Results were analyzed using SPSS (Version 10.1). Spearman's rhos were calculated between perceived risk and the five Weinstein factors. These univariate analyses are the same results that were presented in Study 1 as Linear-by-Linear Chi-square tests. I have presented the relationships as correlations here, to better represent the size of the effect.

Multivariate ordinal regression of the five factors plus the demographic variables (age, gender, ethnicity and marital status) was used to calculate a Pseudo R-squared (McFadden) to examine the amount of variance in perceived risk that could be explained by the five factors combined. SPSS provides three estimates of Pseudo R-squared in ordinal regression; Cox and Snell; Nagelkerke; and McFadden. Pseudo R-squared offers an approximation for R squared but is not as widely useful as the regression R squared (Agresti, 1990). Because there is a degree of uncertainty about the usefulness of Pseudo R-square estimates, I opted to report the McFadden value which provides the most conservative estimate.

## 6.3. Results

### *6.3.1. Correlations between perceived risk and Weinstein's five factors*

Four of the Weinstein factors were significantly related to perceived risk, as described in Study 1 (see Table 6.2). Bowel symptoms showed the strongest relationship, followed by subjective health and family history. Anxiety was significantly associated with perceived risk as were smoking and exercise, although the correlations were small. The "environment" factor represented by the Townsend score did not show a significant relationship with perceived risk.

**Table 6.2 Relationship between perceived risk and Weinstein's five factors**

| | Perceived risk (Spearman's rho) |
|---|---|
| *"Heredity"* | |
| Family history (FDR only) | 0.141* |
| *"Actions and behaviour patterns"* | |
| Smoking | 0.066 * |
| Exercise regularly | 0.083* |
| *"Physiology"* | |
| Bowel symptoms | 0.222* |
| Subjective health | 0.197* |
| *"Psychological attributes"* | 0.136* |
| Anxiety | |
| *"Environment"* | 0.017 |
| Townsend score[18] | |

* significant at $p<0.001$

### *6.3.2. Do Weinstein's five factors explain the majority of the variance in risk perception?*

The model was highly significant $\chi^2(19,9581)=1137.2$, $p<0.001$, but the proportional reduction in $\chi^2$ compared to the 'constant only' model (Pseudo R squared) was 8.1%. This means that only 8% of the variance in perceived risk was explained by the five factors and the demographic factors combined.

[18] Townsend scores were divided into quartiles for analysis. I re-did the analysis using Townsend scores as a continuous variable and it made no impact on the results.

## 6.4. Discussion

The aim of the analyses presented here was to evaluate how well the five factors identified by Weinstein (1984) explained the variation in perceived risk, using both univariate and multivariate analyses. Overall there was strong support for Weinstein's factors with each showing a significant association with perceived risk, with the exception of the "environment" factor. As predicted, bowel symptoms and subjective health, representing the "physical/physiology" factor, and "heredity" showed the strongest correlations with perceived risk. However, "actions and behaviour patterns" also showed significant but small associations. "Psychological attributes" were also significantly related to perceived risk. In each case the size of the correlations was not large. The strongest association found was 0.22 between bowel symptoms and perceived risk. According to Cohen's (1992) estimation of effect sizes for correlations, 0.10 represents a small effect size, 0.30 represents a medium effect size and 0.50 represents a large effect size. The effect sizes in the present study can therefore be regarded as small, with bowel symptoms and subjective health approaching small to medium.

The "environment" factor was not predicted to show a strong association with perceived risk. Previous work (Blalock et al., 1990; Lipkus, Rimer, & Strigo, 1996; Lipkus, Rimer, Lyna et al., 1996) has found the "environment" factor to be infrequently mentioned as a reason for risk judgements which may explain why it has not had a significant influence on perceived risk of bowel cancer in the present study. In the qualitative analysis carried out in Study 4, the types of "environmental" factors that people mentioned in relation to their perceived bowel cancer risk included; spending a lot of time outdoors in the fresh air as reducing their risk, and the things added to food increasing risk. Futher, the previous studies considering bowel cancer categorised reasons such as "all the things they put in food" and "never had a job requiring strenuous work" (Blalock et al., 1990; Lipkus, Rimer, Lyna et al., 1996). It is therefore possible that using an area-level measure of deprivation (Townsend scores) to operationalise the "environment" factor was not appropriate.

A pseudo R-squared was calculated to assess the total amount of comparative risk explained by the five factors combined. The result was 8% of the variance explained. The fact that the five factors combined are accounting for such a small amount of the variance

in perceived risk suggests that there must be a very significant other source(s) of perceived risk not tapped in these analyses.

What is interesting about the results from the present study is how they compare to the conclusions drawn from Study 1 looking at the correlates of perceived risk. In Study 1, the odds ratios from the ordinal logistic regression were large and gave the impression that the predictor variables were strongly related to perceived risk. In the present study however, the associations have appeared less impressive, and when the predictors were included in the Weinstein framework as a model for explaining the variance in perceived risk the five factors had very little impact. This suggests that while the factors identified in Study 1 are influential on perceptions of risk, it is important to realise that they contribute a very small amount in explaining the variance in perceived risk.

The low value of variance explained is somewhat unexpected because the five factors are based on the reasons that individuals cite when asked to justify their risk judgments, and it is difficult to guess what other factors could be possibly accounting for so much variance. One explanation may be that individuals are unaware that other factors are influential in explaining their risk judgements. The literature on unrealistic optimism proposes several cognitive and motivational explanations (e.g. Hoorens, 1994; Weinstein, 1987) which may explain more of the variance in comparative optimism but which are not necessarily accessible to introspection and self report. One motivational explanation is that individuals generate optimistic views about their future risk in order to enhance or maintain self-esteem. In estimating comparative risk, individuals typically think of peers with fewer positive attributes and at higher risk than themselves (Perloff & Fetzer, 1986) i.e. they make a downward social comparison. Downward social comparisons can enhance self-esteem by making one feel good about one's situation relative to the comparison other (Taylor, Wood & Lichtman, 1983). A potential cognitive explanation of comparative optimism is that individuals have biased perceptions of control. Individuals with an internal locus of control tend to show greater optimism relative to those with an external locus of control (Drake, 1987; Hoorens & Buunk, 1993) presumably because of their belief in their own control over their destiny. Finally, lack of experience with a threat may also contribute to optimistic bias because it is harder to imagine how it might affect us (an availability bias; Tversky & Kahneman, 1974). Future work attempting to explain the

variance in optimistic bias would benefit from taking these cognitive and motivational explanations into account, in addition to the five factors.

The low level of variance explained may also be due to statistical reasons. The majority of the predictor variables had a restricted range of outcome levels to include in the model (for example, family history 0-2, smoking 1-2, exercise 1-2, bowel symptoms1-3, and subjective health 1-4), thus the effect is consequently reduced (Howell, 1997).

There are limitations to the present study. One limitation may be related to the methodology. In previous studies participants were given the opportunity to give the reasons for their risk judgments, while in the present study measures representing the five factors were correlated with participants' perceptions of bowel cancer risk. An assumption of the present approach was that participants were influenced by some or all of the five factors. This may not necessarily have been the case and by not giving participants the opportunity to give their reasons for the risk judgments the relationships between predictors and risk perception may have been weakened. However, the present methodology is the only way to assess the important question of how well perceived risk can be explained which the alternative methodology cannot answer.

A further limitation is that the five factors proposed by Weinstein are broad and it is possible that the present study did not fully capture the underlying construct of each of the factors. Using a wider range of measures within each factor may result in more of the variance being explained. In terms of actions and behaviour patterns, factors known to be related to bowel cancer such as intake of folate, fruits, vegetables, fibre and saturated fat (Colditz et al., 2000) were not assessed in this study. The "environment" factor could be extended in future work to include exposures to pesticides, preservatives, pollution, radiation etc. The "psychological" factor could also be more broadly operationalized by assessing personality, values, knowledge and beliefs about being indestructible, for example. However, the "heredity" and "physical/physiology" factors were well measured and it is hard to imagine how these factors could be better operationalized within the confines of self-report measures.

Weinstein's factors provide some clues as to the determinants of perceived risk, however the present study was limited in the operationalisation of the factors and it is possible that with better measurement more variance could be explained. The next two studies attempt to take this forward.

# CHAPTER 7

## Study 4: Exploring the determinants of perceived risk for bowel cancer using qualitative methods

### 7.1. Introduction

Several studies have used a questionnaire format to assess respondents' reasons for their risk judgments (Weinstein, 1984; Aiken et al., 1995), with two of them assessing the coded reasons for bowel cancer risk judgements within Weinstein's five factor framework (Blalock et al., 1990; Lipkus et al., 1996). Lipkus, Rimer, Lyna et al. (1996) found that the majority of their predominantly African American sample attributed their risk (whether high or low) to "psychological" factors such as 'just feeling like you could get it' (35%), followed by heredity (20%), personal actions e.g. diet, exercise, smoking (17%), physiological (12%) and environmental (0.005%) reasons. A further 15% did not know why they had rated their risk as they did. A second study explored bowel cancer risk attributions in a sample of FDR of bowel cancer patients and a control group of FDR of surgical patients (Blalock et al., 1990). Among those with a FDR with bowel cancer, physiology was mentioned most frequently (27%), closely followed by heredity (25%) and personal actions (16%) while the FDRs of surgical patients cited personal actions and physiology with equal frequency (27%) and heredity (10%). Psychological and environmental factors were not mentioned with sufficient frequency in either group, to perform statistical tests and so frequencies were not given. The results of the two studies are therefore completely inconsistent. One might speculate that this is due to the differences in ethnicity of the two samples – the Lipkus, Rimer, Lyna et al. (1996) study was predominantly African American while the Blalock et al. (1990) study was predominantly white, but other factors could be important.

It was felt that qualitative interviews which allowed participants to give reasons for their risk judgments and to express their beliefs about their risk in greater detail would shed more light on the determinants of perceived risk. The qualitative methodology complements the previous quantitative studies by providing a richer and fuller account of people's beliefs about risk. Not only does this technique allow me to further explore the themes already identified as being significant in Study 1, it also permits the discovery of any significant additional factors related to perceived risk of bowel cancer which might account for the unexplained variance in Study 3.

In a literature review, two studies were identified as employing a qualitative approach to examine perceptions of risk for bowel cancer (McCaffery et al., 2001; Weitzman et al., 2001). The focus of Weitzman et al.'s (2001) study was to understand the impediments to bowel cancer screening and so perceived risk was one factor among many that was considered. They used semi-structured focus group interviews, and found participants assumed that family history was a major determinant, and often the sole determinant, of perceived risk. Participants also appeared to assume that risk expression was symptom-dependent. Few knew bowel cancer affects women and there was confusion about lifestyle factors (Weitzman et al., 2001). McCaffery et al.'s (2001) study was nested in the UK FS Trial with the aim of determining why people declined the offer of FS screening, so again perceived risk was not the major focus of the study. In telephone interviews, respondents were found to draw on issues relating to their family history of cancer and bowel cancer, on the absence of bowel symptoms, and on feeling well, to explain their views of personal vulnerability. The picture was therefore similar to that emerging from Weitzman et al's study.

The present study also examined whether people's risk judgements shifted during the course of the interview. It is unlikely that the participants would have spent much time thinking about their chances of developing bowel cancer prior to the interview, as the UK population has been found to have a very limited knowledge of bowel cancer (McCaffery et al., 2003). The interview study therefore provided an opportunity to consider personal risk in detail, over a 45 minute discussion which could well lead to changes in perceptions of risk.

*7.1.1. Aims*

Because this is a qualitative and exploratory study there were no set hypotheses. However, I had several aims:

1. To see if people were willing to make risk judgements
2. To examine the reasons given by participants for their bowel cancer risk judgments and to see how these relate to Weinstein's five factors (1984)
3. To explore the pattern of explanations given between comparative optimists, comparative pessimists and those perceiving their risk to be "the same" as others.
4. To examine whether risk judgements change during the course of the interview

## 7.2. Method

*7.2.1. The qualitative method*

The popularity of qualitative research in health psychology has increased in recent years (Yardley, 2000). This is largely due to the usefulness of qualitative research methods for exploring topics about which little is known or that are complex and therefore difficult to study using traditional quantitative methods. Qualitative research differs from quantitative research in several fundamental ways (Becker, 1996; Denzin & Lincoln 2000; Snape & Spencer, 2003). Quantitative research grew out of the empirical and positivist traditions, and assumes that the methods of the natural sciences are suitable for the study of social phenomenon. Qualitative research, on the other hand, has generally been associated with the interpretativist tradition and places emphasis on understanding how reality is constructed and experienced rather than on observing facts external to human interpretation. Secondly, qualitative research examines social interactions and experiences in natural settings rather than objectifying them in experimental conditions. Qualitative researchers are therefore able to embed their findings within the real world. Thirdly, qualitative research seeks to explore and understand individual's attitudes and behaviour while quantitative research is focused on measurement and statistical comparisons. As a result of this, proponents of qualitative work would argue that quantitative researchers are seldom able to capture an individual's point of view because of their reliance on more remote, inferential empirical methods. Fourthly, qualitative researchers are concerned with

obtaining rich descriptions of the social world while quantitative researchers focus on developing generalizations about populations. A further difference between the two methodologies is in their approach to analysis. Qualitative analysis can be used to identify themes, relationships between themes and explanations while quantitative analysis uses statistics to examine relationships between variables and the strength of these relationships.

Despite the clear differences in the origins and assumptions between qualitative and quantitative methods, both can make a contribution to health psychology research (Snape & Spencer, 2003). For example, qualitative work can be used to validate quantitative work as part of the "triangulation" process (Denzin, 1970). The use of different research methods also allows access to different levels of knowledge to help build a wider picture (Pope & Mays, 1995). This issue of the importance of using different approaches has been summed as, "The prevalence of the distinction between qualitative and quantitative methods tends to obscure the complexity of the problems that face us and threatens to render our decisions less effective than they might otherwise be." Hammersley (1992). However, Richardson (1996) argues that to subscribe to the use of both qualitative and quantitative methods ignores the epistemological basis of the different approaches and employs a pragmatic stance which concentrates on research methods as techniques separated from their philosophical origins. This remains an ongoing dilemma for researchers using both approaches (Snape & Spencer, 2003).

### *7.2.2. Qualitative methods used in Study 4*

This study employed two techniques in analysing the data. The first method, content analysis, was used to identify and quantify the main reasons participants gave for making their risk judgments. Thematic analysis was also carried out to provide a more in-depth account of the themes, and to further explore the differences between comparative optimists, pessimists and participants rating their risk as "the same". Thematic analysis further allowed a greater understanding of the themes and influences on risk perception which could not be captured with content analysis or more quantitative methods. The two techniques complement one another as content analysis is more connected to the quantitative tradition with a strict coding scheme and tests of inter-rater reliability, while thematic analysis places more emphasis on qualitative analysis of these themes in context

(Joffe & Yardley, 2004). By using both approaches the reasons people gave for their risk judgments and the contextual influences on these beliefs were fully explored at multivariate levels of analysis.

Content analysis is a technique for reducing texts into themes or content categories that can then be analysed quantitatively to test hypotheses. It may be considered something of a hybrid between qualitative and quantitative methods. Krippendorff (1980) defines content analysis as, "a research technique for making replicable and valid inferences from data to their context". This definition highlights the marrying of the two techniques with the twin aims of making "replicable and valid inferences" conforming to a more quantitative approach while the in "their context" speaks to a more qualitative tradition. Krippendorff (1980) describes content analysis as having both a mechanical and an interpretative component. The mechanical component involves the physical organisation of the text into categories or themes while the interpretive component entails identifying what categories are meaningful in terms of the questions being asked. When used appropriately, it can combine the advantages of quantitative and qualitative approaches (Morgan, 1993; Yardley, 1997).

Content analysis should be regarded as a process of theory development and hypotheses testing and so it is assumed that from the outset the themes or codes of interest have previously been hypothesised and described. A theme identified within a text may consist of one, several, or many words which have similar meanings. To make valid inferences it is essential that the classification of words or phrases into themes is consistent and so different people should categorise or code the same text to ensure reliability (Weber, 1990). To overcome the ambiguity of word meanings, category definition and other coding rules between different coders, it is recommended that a strict and precise coding scheme is developed (Krippendorff, 1980).

Thematic analysis involves a more in-depth examination of people's risk judgements which may not be captured within the quantification used for content analysis. The thematic analysis allows a more fine grained approach to understanding the differences between comparative optimists, pessimists and those rating their risk as the same. Thematic analysis also permits the exploration of people's reasons in context.

*7.2.3. Participants and procedures*

The study was nested in a larger pilot trial of nurse-led FS screening. The nurse-led FS screening pilot was carried out on 500 men and women aged 60-64 years who were registered with GPs in the catchment area of St Marks Hospital in Harrow. The participants contacted for the present interview study were later invited to attend FS screening although they were not aware that this would happen at the time of the interview.

A list of 60 names and addresses of individuals aged between 60-64 years was obtained from two GP surgeries in the Harrow area of North West London (30 names and addresses per surgery). The list of 60 names and addresses were selected as being the next batch of people who would be invited for screening as part of the nurse-led FS trial.

Participants were initially contacted by letter from the endoscopy unit at St Mark's Hospital in Harrow. The letter informed them that a nationwide bowel cancer screening programme was soon to be introduced and that they were being invited to be interviewed about their interest in bowel cancer screening (see Appendix 4). An information sheet describing the purpose of the study and the format of the interview was included (see Appendix 5). Participants were asked to return an opt-out slip in a prepaid envelope within a week if they did not wish to be contacted about the study. Two weeks after the letters were sent out, I contacted participants by telephone. I described myself as being from the "St Marks Screening Team". I checked that participants had received their letter and information sheet, answered any questions, and if participants were interested, arranged an interview time. Participants were given the options of a home interview or an interview at the Health Behaviour Unit at University College London, with travel expenses reimbursed.

At the start of each interview, participants were reminded about the purpose of the study, asked if they had read the information sheet enclosed with the initial letter (if not they were given a copy to read) and then asked to complete a consent form (see Appendix 6). Participants were reassured about the confidentiality of the interview, told that there were no right or wrong answers, and were asked if they would mind if the interview was tape-recorded.

Interviews were semi-structured and used a topic guide (see Appendix 7). The topic guide was developed based on the research aims. A first draft was discussed with three researchers experienced in qualitative methods who made suggestions about the ordering of questions and the more sensitive ways of asking questions. Each interview began with respondents giving information about their demographic characteristics to get them used to talking and answering questions. The interviews focused on perceptions of risk for bowel cancer, explanations of risk judgements, experience of cancer, and cancer prevention.[19] Participants were asked to estimate their comparative risk for bowel cancer and then asked to explain how they had made that judgement. Participants were given general prompts such as, "Why is that?"; "Can you tell me a little more about that?"; "Are there any other factors that influenced your judgement?" Potential reasons (e.g. family history, health behaviours) were not given as prompts. Interviews took around 45 minutes.[20]

The first five interviews were initially regarded as pilots to test the topic guide. After completing the five interviews it was decided that the topic guide was adequately covering all the areas of interest and was used on all remaining interviews. The first five interviews were therefore included in the main analysis. I carried out all the interviews, and they were conducted from October to December 2003.

Ethical approval was granted by the Harrow Research Ethics Committee as part of the larger scale study of nurse-led FS screening.

### *7.2.4. Analysis*

All participants agreed to the interview being tape-recorded. The interviews were transcribed verbatim. Transcripts were originally formatted into Word and then transferred to the software Atlas.ti. Atlas.ti is a software package designed for the qualitative analysis

[19] Participants were also asked about their perceptions of risk for breast cancer, prostate cancer and cancer in general, but analysis of these areas was beyond the scope of this thesis.
[20] I also asked people about their interest in bowel screening and showed them a leaflet about FS bowel screening. This information was collected for the researchers working on the nurse-led trial and so is not discussed in this thesis.

of large bodies of textual data. In this study it was primarily used to organise the quotes into categories.

Five randomly selected transcripts were studied in detail to identify the key themes or codes. Weinstein's (1984) five factors provided useful categories although additional themes also emerged. A coding sheet was developed based on the five factors described by Weinstein and the additional themes. A detailed coding manual was written to make explicit how transcripts were to be coded (see Appendix 8). The coders read through the coding manual and then discussed the meaning of the coding categories to identify any areas of ambiguity. The first 10% of transcripts (2 transcripts) were coded independently by two researchers (KR and AS) and 92% inter-rater agreement was obtained. The kappa inter-rater reliability statistic (Cohen, 1960) was slightly lower at 0.72 but still represented an acceptable level of agreement (Landis & Koch, 1977). In both cases inter-rater reliability was calculated before differences were discussed. The remaining data were coded by the researcher (KR).

## 3. Results

### *7.3.1. Respondents*

In total, twenty people were interviewed, see Table 7.1. Sixteen interviews took place in participants' homes. Three people opted to come to the Health Behaviour Unit at University College London for the interview. One person was interviewed over the phone as that was his preference. Two people were excluded from the analyses because the tape-recorder failed and the interviews were not recorded.

Six people returned the opt-out slip indicating that they were not interested in taking part, see Table 7.1. A further ten people declined the invitation to be interviewed when telephoned. Ten people were non-contactable by phone either because the telephone number provided by the GP surgery was not recognised or there was no telephone number. In both cases attempts were made to obtain the correct telephone number using the British Telecom directory but no alternative numbers were found. Three people were not

contacted after five attempts. On six occasions a telephone conversation revealed that the person no longer lived at the address. Two people declined the invitation to be interviewed because they felt their English was not fluent enough. One person was found to have learning difficulties and their carer felt it was not appropriate for them to be interviewed. One person had recently suffered a stroke and was too ill to be interviewed. One person had died several years ago.

**Table 7.1: Results of all contacts made**

| | n (N=60) | % |
|---|---|---|
| Interviewed | 20 | 33.3 |
| Returned 'do not contact slip' | 6 | 10 |
| Not interested when telephoned | 10 | 16.7 |
| Telephone number not recognised | 7 | 11.7 |
| No telephone number | 3 | 5 |
| Not reached after 5 attempts | 3 | 5 |
| No longer at address | 6 | 10 |
| Inadequate English | 2 | 3.3 |
| Learning disability | 1 | 1.7 |
| Too ill | 1 | 1.7 |
| Died | 1 | 1.7 |

*7.3.2. Demographic characteristics of respondents*

Respondents were 12 women and 6 men aged between 60 and 63 years, with a mean age of 62 years (sd=1.27), see Table 7.2. The majority of respondents were white (n=14) and married (n=13). Respondents had a range of educational qualifications from no qualifications (n=2) to university degree level (n=2), with the largest proportion having O-levels or equivalent (n=6). Education details were not obtained from four participants. In each case the interviewer asked about education but the respondent failed to provide details and the interviewer did not probe further. Seven participants were working full-time and one woman cared full-time for her terminally ill husband. Seven respondents were either semi-retired (n=3) or retired (n=4). Three participants described themselves as not working at the moment.

**Table 7.2: Demographic characteristics of participants**

| | n (N=18) | % |
|---|---|---|
| Gender | | |
| Female | 12 | 66.7 |
| Male | 6 | 33.3 |
| Ethnicity | | |
| White British | 10 | 55.6 |
| White Irish | 3 | 16.7 |
| White Eastern European | 1 | 5.6 |
| Black African | 1 | 5.6 |
| Black Caribbean | 3 | 16.7 |
| Marital status | | |
| Married | 13 | 72.2 |
| Divorced | 1 | 5.6 |
| Widowed | 2 | 11.1 |
| Single | 2 | 11.1 |
| Education | | |
| No qualifications | 2 | 11.1 |
| O level or equivalent | 6 | 33.3 |
| A level or equivalent | 1 | 5.6 |
| Vocational training | 3 | 16.7 |
| Degree | 2 | 11.1 |
| Missing | 4 | 22.2 |
| Employment status | | |
| Working full-time | 7 | 38.9 |
| Full-time carer | 1 | 5.6 |
| Semi-retired | 3 | 16.7 |
| Retired | 4 | 22.2 |
| Not working | 3 | 16.7 |

### *7.3.3. Comparative perceived risk*

The first risk question asked participants to compare their chances of getting bowel cancer with others of the same sex and age (the standard comparative risk question). Five participants felt at lower risk (28%), nine believed they were at the same level of risk (50%), and four respondents thought they were at higher risk than their peers (22%).

### *7.3.4. Explanations of comparative risk judgments*

Ten respondents were confident in answering the comparative bowel cancer risk question and appeared to provide their answer with ease. Eight respondents were slightly more hesitant, but all provided a risk judgement. After respondents made their risk judgements, I asked them, "How did you answer that question? Can you tell me the sorts of things you thought about in answering that question?" Respondents mentioned a range of risk factors when asked to describe how they made their risk judgments. Even if respondents saw their risk as "the same", most were able to explain their reasoning, see Figure 7.1 and Table 7.3. The last two columns of Table 7.3 indicate whether the risk factor was seen as risk increasing or risk decreasing. Explanations were grouped into Weinstein's five factors with the additional factors of "chance" and "don't know"[21].

*Actions and behaviour patterns.* Actions and behaviour patterns were the most frequently mentioned category in explaining bowel cancer risk judgments, see Figure 7.1 and Table 7.3[22]. By far the most cited factor within this category was diet with nine respondents giving this as an explanation. Diet was mentioned exclusively as a risk decreasing factor. *"Food-wise we eat quite healthy food..... I've got a feeling, you know, that so far there's no problem so it's got to be below average"* (016); *"But I do eat very healthily, fresh vegetables and, and you know I'm quite a healthy eater"* (012). Eating plenty of fruits, vegetables, fibre or roughage, and limiting intake of red meat and fatty foods were all

[21] Instances of each factor are coded per person e.g. if a participant mentions diet twice it was only counted once. The focus is on instances and not intensity.

[22] Ideally with Content Analysis one would use Chi Square tests to examine the differences between groups statistically. Because this study had only 18 respondents and many factors were mentioned infrequently it was not possible to carry out a Chi Square test without violating the assumption that there must be five counts per cell. Therefore the pattern of results is described but is not confirmed statistically.

mentioned as reducing risk. There was also a belief among some participants (n=4) that eating a 'balanced' diet was beneficial, *"I try and have a healthy diet, which is, a balanced diet, fruit everyday and vegetables everyday. That sort of thing. Very little of the stuff that's supposed to be bad for you, as much as possible anyway"* (005). One participant went on to explain why she thought having a varied diet was important, *"I think of my dear old mother's advice about a little of what you fancy doing you good is probably very sensible advice because it means you spread the risk if you like, if you spread the variety of what you're eating"* (010). So to this woman, not only was it important to eat a range of foods to maintain good health, she believed that by doing so one would avoid problems if a certain food was found to be harmful (e.g. in the past beef, eggs) because it would represent a small proportion of your overall diet. No-one offered diet as a cause of high risk.

Exercise was mentioned by two participants as reducing their chances of getting bowel cancer. *"I'm very fit and I do conservation work at the weekends and so my lifestyle is better than most people who are sedentary these days"* (005). This quote also shows that the participant is making a downward social comparison by comparing himself to a stereotyped view of others who are inactive, and is ignoring the fact that there may be others who are actually more active than himself. The other respondent who mentioned that being physically active reduced his risk for bowel cancer provided an interesting explanation of the mechanism through which exercise is beneficial, *"Because I think, um, bowel's obviously a muscle and the way it operates...keeping fit and healthy gives it the chance to keep healthy itself rather than relax and not do anything"* (006). No participant offered their inactive lifestyle as a risk increasing factor.

Alcohol was mentioned by two respondents in explaining their risk judgement. One respondent believed that because he drank in moderation this would decrease his chances, *"I do drink but not to excess. I probably drink weekends but I don't drink mid-week"* (009). Another respondent believed that her drinking would increase her risk of bowel cancer, *"I drink. Classic!"* (012).

Smoking was only mentioned by one participant as influencing their risk judgment. Surprisingly, this respondent mentioned her smoking habit as increasing her risk. This respondent seemed particularly aware of the health behaviours that increased her risk, *"I*

*would say with my lifestyle I would be a person at risk. Definitely, without a doubt. Because I smoke, I drink. Classic!"* (012). Respondents were not asked specifically about their smoking habit, but 10 respondents mentioned being non-smokers although they did not refer to this when explaining their risk estimate.

Sexual behaviour was given as an explanation by one respondent. The respondent believed because she had had only one sexual partner for 30 years this reduced her risk of developing bowel cancer, *"..it might sound silly but if you go around with a lot of like men and so on, ever since 30 years or whatever I've been with my husband, I don't stray with you know Tom, Dick or Harry, I just stay put"* (001).

*Heredity.* Heredity or family history was given as an explanation for risk judgements by seven participants. Family history was mentioned as both a risk increasing (n=3) and a risk decreasing factor (n=4). Among respondents citing it as a risk increasing factor, two had a family history of bowel cancer, *"My father died of bowel cancer so, going on the hereditary factor I suppose I'm probably a bit more at risk"* (020). A third participant who mentioned family history as increasing her chances did not have a family history of bowel cancer specifically, but had a history of other forms of cancer in her family and felt at risk of all types of cancer. This respondent also had a theory that because cancer had skipped a generation she was particularly at risk, *"Because my mum is alive and her brother is alive and they have nothing diagnosed. Cancer has skipped a generation so the next generation will be me and my children...I think are a risk, very high, with any form"* (014). Those respondents referring to family history as a risk decreasing factor spoke of the absence of bowel cancer within their family, *"It doesn't run in the family"* (017).

*Physical/physiology.* Symptoms and general health were frequently given as reasons for perceived risk judgements (n=10). Two had been through a bowel examination which they felt reduced their risk as they had been given the 'all clear'. A lack of symptoms and feeling well were commonly given reasons for risk judgements and were mentioned by eight participants as reducing their risk of developing bowel cancer, *"I've never had any problems with that area of myself, ever"* (004); *"I've got very good bowel movements, no stomach pains"* (016); *"Only that I've been reasonably healthy and other than that I don't really have an answer. I've been reasonably healthy"* (009). Two respondents mentioned

symptoms as increasing their risk. One respondent had a history of diverticular disease and the other who saw it as a risk increasing factor said, *"Em, yes I have trouble. Mostly with the kidneys but I've also had trouble with the bowels a bit. Not a tremendous amount, but eh.."* (015).

Age was mentioned as a factor by four participants. In three out of the four cases age was regarded as a risk increasing factor, *"if you live a bit longer, your risk of getting it is probably higher"* (013). One woman who saw her age as increasing her risk reflected on her experience as a nurse, *"Maybe because I see women of my age, I work as a nurse in a hospital, so I, I, have seen women of my age normally getting this at their later ages"* (007). The one respondent who saw age as decreasing her risk of developing bowel cancer gave a rather confused explanation, *"So the older you get, we're hoping the chances are going to get less. We know that's not true but eh, that's my form of thinking"* (017). From the following explanation it seems that this woman is confusing incidence with survival, *"I'm assuming that if things kick off they are a little bit maybe slower when you're older. Now I don't know, I may be quite wrong, in that form of thinking but I'm thinking and if you get these things younger.....because you're young and because everything is, you know, your hormones and everything is going that you might develop at a quicker stage"* (017).

*Psychological factors.* Psychological explanations were not frequent and were only mentioned on three instances. In each case the participant stated that they just hoped they wouldn't get bowel cancer e.g., *"I hope, I've been realistic I would have hoped unlikely"* (019); *"I'm hoping below average"* (009). I do not believe these are strong examples of psychological explanations because I did not understand from respondents that their hope was the reason they would not develop bowel cancer. However, such explanations are coded as "psychological" here because previous studies have categorised similar expressions e.g. "trust that I won't get it" (Blalock et al., 1990) in this way. It was my impression that in the three respondents "hoping" they wouldn't get it, it was more just an expression with little weight behind it, rather than a strong positive attitude which they thought would keep them well.

*Environmental factors.* Environmental influences on risk judgments were cited on four occasions. One respondent believed that because he spent a lot of time outdoors his

chances of developing bowel cancer were reduced, *"spending plenty of time outside which I think gives you immunity to most ills generally"* (005). The other respondents who mentioned environmental factors spoke of it in relation to food. One respondent believed chemicals in food increased her risk, *"I mean we don't know what manufacturers are putting into the food....I mean we can't plant our crops yourself.....So we don't know what is being put into either fertilizing the soil for crops or what. We don't know"* (014). Another participant believed that because she avoided eating tinned food this reduced her risk, *"Um there is things in tins that can really mess up your health really. And um ever since I was growing back home in Jamaica, that's where I'm from, we don't eat a lot of tinned food. Anything we eat is sort of fresh"* (001). A fourth participant mentioned eating organic food as reducing his risk, *"I try to have all these organic foods nowadays"* (009)[23].

*Chance.* Chance was given as an explanation in 4 instances, all for higher risk. In each case chance was given as a counter-point following on from a discussion of risk reducing factors, *"I'm not saying it can't happen because I mean, anything can happen to everybody"* (001).

*Don't know.* Although every participant provided a response to the comparative risk question, when asked to give a reason for their risk judgment many, (n=7) said that they didn't know. There were two types of "don't know" responders; one who initially said they didn't know but went on to provide reasons (n=5), and another group who simply did not know and could provide no explanation other than they didn't know (n=2) *"Bowel cancer, I just don't know"* (003); *"I can't say for sure that it would be below average but I couldn't say that I would necessarily be at risk because I'm not, I don't know what causes it. And presumably nobody knows what actually causes it, but I don't know enough about that particular type of cancer to be able to give a considered view on my own chances of developing."* (010).

[23] The reasons given regarding the things that are added to food were coded under 'environment' rather than under actions and behaviour patterns because previous studies have coded them in this way (Blalock et al., 1990; Aiken et al., 1995; Lipkus, Rimer, Lyna et al., 1996).

**Figure 7.1: Reasons given for comparative bowel cancer risk judgments**

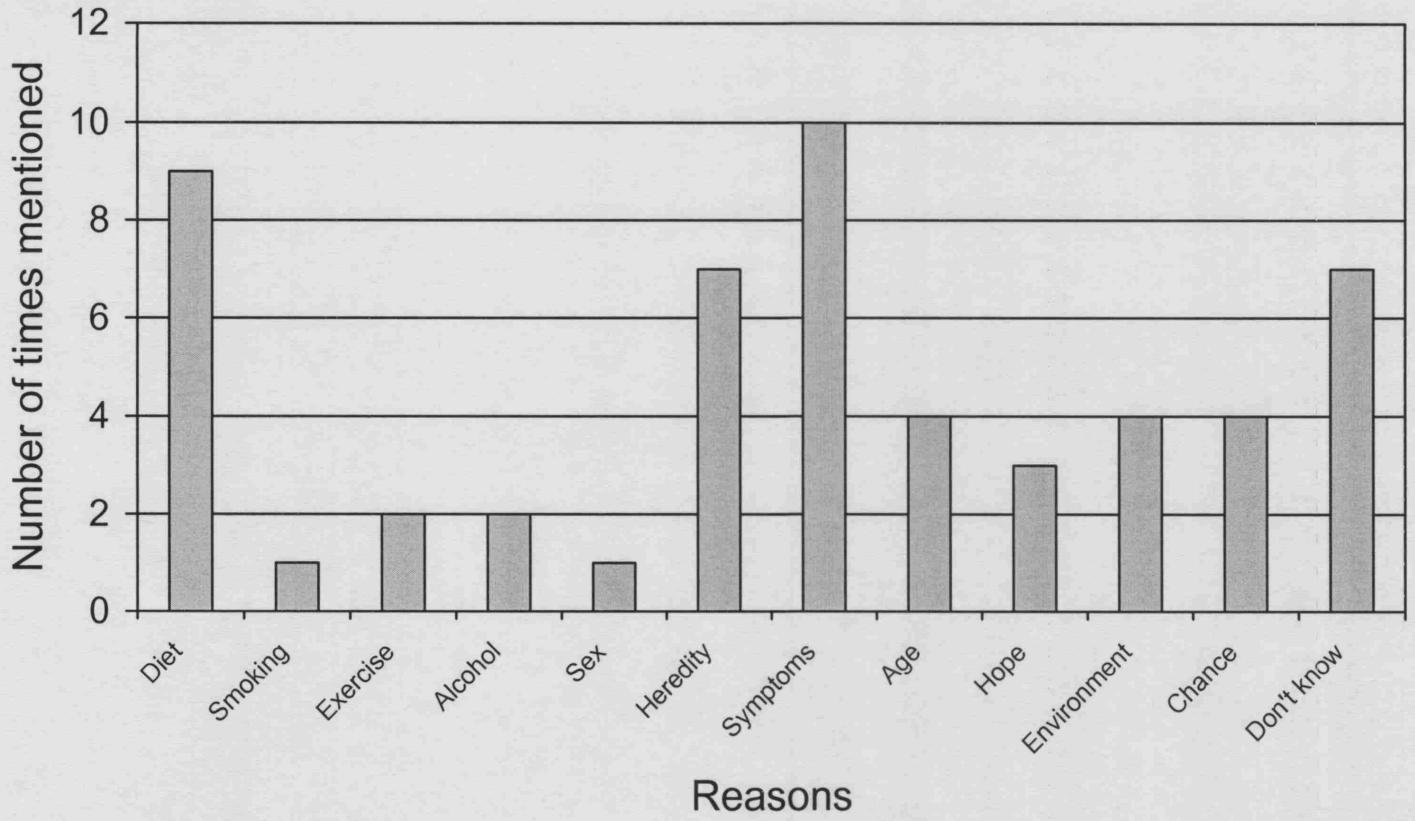


**Table 7.3: Reasons given for comparative bowel cancer risk judgements**

| | N | Risk decreasing | Risk increasing |
|---|---|---|---|
| "Actions and behaviour patterns" | | | |
| Diet | 9 | 9 | 0 |
| Smoking | 1 | 0 | 1 |
| Exercise | 2 | 2 | 0 |
| Alcohol | 2 | 1 | 1 |
| Sex | 1 | 1 | 0 |
| "Heredity" | 7 | 4 | 3 |
| "Physical/physiology" | | | |
| Symptoms/general health | 10 | 8 | 2 |
| Age | 4 | 1 | 3 |
| "Psychological factors" | | | |
| Hope | 3 | 3 | 0 |
| "Environment" | 4 | 3 | 1 |
| Chance | 4 | 0 | 4 |
| Don't know | 7 | - | - |

### *7.3.5. Exploring the explanations given by comparative optimists, pessimists and "the same"*

Table 7.4 presents the pattern of results between risk judgements and risk explanations and divides the explanations into risk increasing and risk decreasing factors. From Table 7.4 it can be seen that almost three times as many risk decreasing (n=32) factors were mentioned compared with risk increasing factors (n=11). Comparative optimists did not mention one single risk increasing factor. Those perceiving their risk to be 'the same' mentioned five risk increasing factors and comparative pessimists mentioned six risk increasing factors. Overall, comparative pessimists mentioned more risk increasing than decreasing reasons and those rating their risk as 'the same' mentioned more decreasing than increasing factors.

*Actions and behaviour patterns.* In every case comparative optimists mentioned only risk reducing behaviours. Comparative pessimists also cited diet as decreasing their risk but one comparative pessimist saw smoking and drinking as increasing her risk. Among those who saw their risk as average, two mentioned diet as reducing their risk and one cited exercise as decreasing his risk. Overall, it was only amongst the comparative pessimists that actions and behaviour patterns were mentioned as increasing risk. Those who regarded their risk as lower or the same relied solely on risk reducing explanations.

*Heredity.* Family history was mentioned by four comparative optimists as being a risk decreasing factor and by two comparative pessimists as a risk increasing factor. One respondent rating their risk as 'the same' cited family history as increasing risk.

*Physiology.* All five comparative optimists mentioned the absence of symptoms and feeling well as decreasing their risk for bowel cancer. One of the five also believed that being older reduced her risk. Two of the comparative optimists mentioned having had their bowel examined in the last couple of years and being given the *"all clear"*. It is therefore not particularly surprising that they perceived their risk to be lower than average.

Amongst the comparative pessimists, one mentioned age as increasing their risk, one mentioned having symptoms as increasing their chances and a third cited an absence of symptoms as decreasing her risk. In the third case, the participant had a personal history of Hodgkin's Disease so although she mentioned not feeling particularly vulnerable to bowel cancer as she had no symptoms, she perceived her history of cancer as increasing her risk.

Two participants who rated their risk as 'the same' mentioned age as a factor in making their personal risk judgment. In one case age was perceived as increasing risk while in the other, any age was seen as being at risk, *"I mean I know with prostate cancer....men are more likely to get it as they get older, I can't see why the bowel because I'm medically ignorant um is necessarily age related at all"* (019). Two respondents mentioned the absence of symptoms as reducing their risk. One respondent referred to his history of diverticular disease as increasing his risk. Among those judging their risk as 'the same', heart disease was mentioned by five out of the nine in this group as being something that

they felt more prone to either due to a personal history or a strong family history. This factor may well have contributed to their ambivalent beliefs about bowel cancer.

*Psychological factors.* In all three risk judgment categories, one respondent mentioned *"hoping"* that they would not get bowel cancer.

*Environmental factors.* Environmental factors were only mentioned by comparative optimists and those rating their risk as 'the same'. The two comparative optimists spoke of avoiding eating tinned food and eating organic food as decreasing their risk. One participant rating their risk as 'the same' regarded spending time outside as decreasing risk while the other case believed chemicals in food increased risk.

*Chance.* Chance was most often mentioned in 'the same' category. It was not mentioned at all as a factor by comparative pessimists and only one comparative optimist cited chance in explaining their risk judgment. This pattern of results is perhaps understandable as those rating their risk as 'the same' are most likely to believe they may or may not get it and therefore chance plays a role, while those who perceive their risk as lower or higher than average are more likely to have more concrete explanations.

*Don't know.* Those rating their risk as 'the same' were most likely to mention that they *"don't know"* when making their risk judgment. No comparative pessimist gave *"don't know"* as a response. Two comparative optimists mentioned not knowing initially but went on to provide a variety of explanations. The two respondents who were unable to provide any reasons for their risk judgments both fell into 'the same' category.

**Table 7.4: Relationship between perceived comparative risk and risk explanations for risk decreasing and risk increasing factors**

| | | Perceived risk | | |
|---|---|---|---|---|
| | N | Lower | The same | Higher |
| **Risk decreasing** | | | | |
| "Actions and behaviour patterns" | | | | |
| Diet | 9 | 5 | 2 | 2 |
| Smoking | 0 | 0 | 0 | 0 |
| Exercise | 2 | 1 | 1 | 0 |
| Alcohol | 1 | 1 | 0 | 0 |
| Sex | 1 | 1 | 0 | 0 |
| "Heredity" | 4 | 4 | 0 | 0 |
| "Physical/physiology" | | | | |
| Age | 1 | 1 | 0 | 0 |
| Symptoms/general health | 8 | 5 | 2 | 1 |
| "Psychological factors" | | | | |
| Hope | 3 | 1 | 1 | 1 |
| "Environment" | 3 | 2 | 1 | 0 |
| **Total risk decreasing** | **32** | **21** | **7** | **4** |
| **Risk increasing** | | | | |
| "Actions and behaviour patterns" | | | | |
| Diet | 0 | 0 | 0 | 0 |
| Smoking | 1 | 0 | 0 | 1 |
| Exercise | 0 | 0 | 0 | 0 |
| Alcohol | 1 | 0 | 0 | 1 |
| Sex | 0 | 0 | 0 | 0 |
| "Heredity" | 3 | 0 | 1 | 2 |
| "Physical/physiology" | | | | |
| Age | 3 | 0 | 2 | 1 |
| Symptoms/general health | 2 | 0 | 1 | 1 |
| "Psychological factors" | | | | |
| Hope | 0 | 0 | 0 | 0 |
| "Environment" | 1 | 0 | 1 | 0 |
| **Total risk increasing** | **11** | **0** | **5** | **6** |
| Chance | 4 | 1 | 3 | 0 |
| Don't know | 7 | 2 | 5 | 0 |

*7.3.6. Do risk judgements change as a result of the interview?*

At the end of each interview, I asked respondents to rate their comparative bowel cancer risk again. None of the comparative pessimists, or those rating their risk as 'the same' changed their risk estimate. However, four out of the five comparative optimists judged their risk to be 'the same' at the end of the interview.

*7.3.7. In-depth analysis*

To try to understand fully why respondents made the risk judgments they did, I looked beyond just the factors they have mentioned in explaining their perceived risk and also explored other potential influences such as how close they were to family members and their experience of cancer through friends. In this final section I use thematic analysis to consider in-depth the differences between comparative optimists, pessimists and those rating their risk as the same, in terms of family history and experience as these themes have emerged as being particularly influential on risk judgement.

*Family history.* Three out of the five comparative optimists reported having no family history of cancer, and therefore mentioned it as a risk decreasing factor. One comparative optimist did have a family history of cancer but not of bowel cancer specifically and so she did not feel at risk genetically. A fifth comparative optimist did not mention heredity in explaining his risk judgement although he had a positive family history of cancer.

The two comparative optimists who had a family history of cancer provided very clear explanations as to why that family member had developed cancer. In talking about her mother having stomach cancer 017 said, *"Well she, she had MS. I mean she died in.....about 30, I'm trying to think back, it's so many years ago, about 38 years ago.....but she had MS as well so whether, you know, I often wondered was, you know does a sedentary life, she never walked for 26, 28 years, is it a sedentary life kick off the other things, you know, if you're not as healthy as you could be if you know what I mean"* (017). It can be seen from this quote that this woman lost her mother a very long time ago, her mother had MS and she hypothesises that her mother's sedentary life may have contributed in the development of the cancer. It is therefore possible that this woman sees

very few similarities in terms of her health and her mother's health and regards her mother's sedentary life and compromised health as the main cause of her stomach cancer. Seen from this perspective it is perhaps understandable that this respondent did not feel vulnerable to bowel cancer despite a close family relative suffering from cancer. Similarly, the second comparative optimist with a family history described how his father died 42 years ago, *"He died of cancer of the liver, and well his body was racked with cancer, but, and he smoked very heavy. But at the same time he was one of the misfortunate ones that was in the First World War and he had tear, he had mustard gas and he was a very sick man"* (009). This respondent is attributing his father's cancer to mustard gas exposure and also mentions that his father smoked heavily. The respondent therefore does not perceive any personal susceptibility to cancer due to genetic factors because he regards his father's cancer as being caused by environmental exposure and smoking. These two respondents are similar in that they both have clear explanations in their minds as to why their relative developed cancer and in both cases these explanations do not apply to them personally. In addition, both respondents lost their relatives many years ago. These two factors may contribute to these participants perceiving their personal risk of developing bowel cancer as lower than average.

The two comparative pessimists providing heredity as an explanation both had a family history of bowel cancer. They were the only two participants to have a family history of bowel cancer specifically. A third comparative pessimist had both a family history of cancer and a personal history of Hodgkin's Disease. The fourth also had a strong family history of cancer. It is understandable that the two respondents with a family history of bowel cancer mentioned this as a risk increasing factor. The other two comparative pessimists did not mention family history in explaining their perceived risk but it can be suggested that their positive personal and family histories may have subtly influenced their risk judgements.

Only one respondent who rated their risk as 'the same' mentioned family history. This respondent saw her family history of cancer as increasing her chances of developing bowel cancer. Five other respondents who rated their risk as 'the same' also had a family history of cancer but did not mention this as a factor in explaining their risk. One reason why a family history has not influenced this groups' perceived vulnerability may be their distance

from the family member who has been affected. In one case a respondent's relatives lived in Ireland so she had little experience of their illness, while another described his uncle dying between 30-40 years ago. Another who appeared to have been close to her relatives who had had cancer did not feel at risk for bowel cancer because she felt if she were to get cancer she would develop breast or cervical as those were the cancers she felt most vulnerable too, although none of her relatives had suffered from these two types of cancer. One respondent who described her risk as 'the same' had a strong family history with her sister dying of cervical cancer in her 50's, her brother dying of lung cancer and her mother having cancer of the kidney, however she said, *"from a genetic point of view, I don't think I'm overly prone"* (010). This participant does not perceive a genetic link despite three first degree relatives being affected. I asked her directly if she felt prone to cervical cancer because of her sister's history and she replied, *"No, I don't think so. I mean, her lifestyle was different from mine anyway."* She said that the cause of her brother's lung cancer was smoking which she gave up many years ago, *" he was a very heavy smoker so you know, that's the main reason"*. In both instances the respondent sees herself as dissimilar to her siblings and this may well explain why she does not perceive her risk to be higher. In describing her mother she says, *"Oh my mother actually had cancer when she was in her late seventies. One of her kidneys was affected and eh, she had it removed. But as I said she was in her late seventies and eh, she survived for another 6 years after that and she didn't die of cancer"*. Again, it seems that due to her mother's age and the fact that cancer didn't kill her mother, the respondent does not feel particularly vulnerable.

*Experience.* Following on from family history is the influence of experience. 'Experience' is conceived as capturing not only contact with non-blood relatives and friends but also the nature of the experience.

On the whole, comparative optimists had little direct experience of cancer. One comparative optimist said she did not know anyone who had had cancer and her only experience was through what she saw on television and read in the newspaper (surprising in a woman aged 60). Two mentioned knowing people who had bowel cancer. In one case it was a friend who the respondent described as eating a diet of *"rubbish"*, and in the other it was a work colleague who was described as coping very well with the illness and having been in remission for over three years. In the first case the respondent seemed to suggest

that her friend's bowel cancer was caused primarily by his poor diet and because she ate a good diet she perhaps perceived herself to be at lower than average risk. In the second case, the respondent's work colleague presented a relatively encouraging image of bowel cancer which may have led him to feel less prone.

Comparative pessimists, on the other hand, presented quite a different experience. One respondent described the death of his uncle from bowel cancer as being, *"particularly tragic, it upset everybody"* (015), he also described his mother-in-law's death from bowel cancer, *"Poor women died in absolute agony, it was terrible. Went on months and months"* (015). The participant presented two very vivid images of people he has known who have died of bowel cancer. The images are particularly traumatic and this may well be influencing how he feels about his vulnerability to bowel cancer. Another comparative pessimist who had lost two friends to bowel cancer explained *"I've lost dear friends.....when I look at their lifestyle and my lifestyle and everything, I can definitely see a connection"* (012). It seems that the similarity in lifestyle between herself and her friends has led this respondent to feel particularly vulnerable.

Of those rating their personal risk as 'the same', eight out of nine had not been close to someone who had bowel cancer. Five out of the nine had experience of some one close suffering from a different type of cancer, but this seems to have had little impact on their perceptions of risk for bowel cancer.

*Overall impression.* My overall impression of the comparative pessimists was that they were a lot more grave on the subject of bowel cancer than either the comparative optimists or those rating their risk as 'the same'. It seemed to matter more to them. However, I do not think their risk judgements were related to a general negative disposition, for example one comparative pessimists was amongst the most upbeat of the respondents.

## 7.4. Discussion

The aim of this study was to explore the reasons given by participants for their bowel cancer risk judgments in an attempt to understand better why in using quantitative data I explained so little of the variance in perceived risk. The study examined the usefulness of

Weinstein's (1984) five factor framework in organising the breadth of reasons given to explain perceived vulnerability to bowel cancer, and to determine whether the factors captured all the explanations given. The study also explored whether risk estimates changed during the course of the interview. The final aim was to explore the pattern of explanations given and any other influences on perceived risk between comparative optimists, comparative pessimists and those perceiving their risk to be 'the same' as others in an attempt to discover what makes someone believe they are at lower/the same/higher risk than average.

In total, participants mentioned twelve separate reasons for their judgements. Weinstein's (1984) five factor framework proved to be useful in categorising the reasons as each of the five factors were mentioned, with the additional factor of 'chance' identified. "Don't know" was also a frequent initial response. It was possible to detect differences across those seeing their risk as lower/the same/higher with comparative optimists citing only risk decreasing factors, and the other two groups more inclined to mention both risk increasing and decreasing factors. The in-depth analysis revealed that it was principally those who had little direct experience of someone suffering from cancer who were most comparatively optimistic.

### *7.4.1. Explanations of comparative risk judgments*

The most frequently mentioned factor was "actions and behaviour patterns" with this being cited on 15 occasions. By far the most mentioned health behaviour was diet (n=9) with others being mentioned fairly infrequently (smoking n=1, exercise n=2, alcohol n=2, sex n=1). In line with previous work (Weinstein, 1984; Blalock et al., 1990; Aiken et al., 1995), actions and behaviour patterns were mentioned in a biased way with thirteen out of fifteen instances being described as risk reducing. In every case diet was mentioned as a risk decreasing factor[24]. The pattern of results for health behaviours showed that respondents lacked knowledge about bowel cancer. Diet was perceived to be the most important health behaviour and while there is evidence that diet plays a causal role in the aetiology of bowel cancer it is one of many factors (Colditz et al., 2000). On the whole,

[24] As an observer it seemed highly unlikely that all nine participants who claimed to have a healthy diet actually did, and it was clear that diet was mentioned in a very biased manner.

few respondents recognised that smoking, exercise and alcohol can influence risk and not a single respondent mentioned body weight as influencing their risk judgment, despite many appearing to be overweight. From a practical point of view these are all factors that could be addressed through public health education so that people are made aware of the risks and are able to take precautions.

"Physical/physiology" was the next most mentioned factor. Symptoms or general health were cited on ten occasions and age on four occasions. Symptoms and general health were mentioned in a biased manner with eight respondents citing these as risk decreasing factors and only two respondents mentioning them as risk increasing. This was in line with some previous work (Weinstein, 1984; Aiken et al., 1995), although in assessing respondent's reasons for their bowel cancer risk judgements in a quantitative study, Blalock et al. (1990) reported that "physiological" factors were mentioned in a more even-handed manner. In the present study age was regarded in three out of four instances as risk increasing suggesting that respondents recognised that their older age increased their risk.

"Heredity" was mentioned on seven occasions and was seen in a much more balanced light with four instances of risk decreasing and three of risk increasing. Previous work has also found family history to be mentioned in a much more balanced manner (Weinstein, 1984) although in a quantitative study of breast cancer risk heredity was three times more likely to be mentioned as risk decreasing (Aiken et al., 1995). While having a family history was fairly frequently mentioned, it was also ignored and discounted by several respondents.

"Psychological factors" per se (e.g. stress) were not mentioned, but 'hope' was mentioned on three occasions and in each case the respondent expressed a hope that they would not get bowel cancer. To me, their expression that they "hoped" they would not get it reflected a weak belief, and not a belief that they thought hope would protect them in anyway. In a quantitative study of African American's perceived risk of bowel cancer, psychological factors e.g. "feel that I could get it" were the most mentioned category (Lipkus, Rimer, Lyna et al., 1996), so it was somewhat surprising that these were not more frequently mentioned in the present sample.

"Environment" was mentioned by four respondents. In three cases it was seen as risk reducing and the other it was cited as increasing risk. It was primarily mentioned in relation to food with three of the four cases describing contamination of food or the avoidance of such a risk by eating organic food. Other studies have found "environment" to be a little endorsed category (Aiken et al;, 1995; Lipkus, Rimer, & Strigo, 1996; Lipkus, Rimer, Lyna et al;, 1996).

Two other responses were mentioned as reasons. The first was "chance" which was mentioned on several occasions, and tended to be given as a counter-point following a discussion of risk reducing factors. "Chance" has been found in previous studies (Aiken et al., 1995; Lipkus, Rimer, & Strigo, 1996). The second was "don't know" which was mentioned by seven respondents and has been noted as an additional category in previous research (Lipkus, Rimer, Lyna et al., 1996). The respondents who said they didn't know the reasons for their risk judgment fell into two categories. The first (n=2) were completely unable to provide any reason while the second (n=5) initially said, "don't know" but went on to provide reasons. This is an important finding in terms of future work assessing comparative risk. There is some debate when asking comparative risk questions as to whether "don't know" should be given as a response option. The results from the present qualitative study suggest that amongst those who aren't sure, if they are encouraged to think about it, the majority are able to generate reasons. It is also interesting to note that not one respondent was unable to provide an answer to the comparative risk question. This suggests that even amongst the two respondents who failed to provide any reasons, some process guided their decision (as they provided an answer to the comparative risk question without great difficulty) even if they were unaware or unable to verbalise exactly what.

Analysing the reasons that respondents gave for their comparative bowel cancer risk judgements is helpful in interpreting the results of the quantitative analysis of the five Weinstein factors. In Study 3 the attempt to operationalise Weinstein's (1984) five factor framework found that only 8% of the variance in perceived risk was explained. To a certain extent, the present qualitative study has illuminated why the operationalisation of Weinstein's framework was not more successful. Study 3 did not measure diet and this has been shown to be a frequently mentioned factor in bowel cancer risk judgments. Instead, Study 3 assessed "actions and behaviour patterns" with simple measures of smoking and

exercise. The present study revealed that few individuals took these health behaviours into account when making their risk judgments. The "environment" factor in Study 3 was operationalised using a measure of area-level deprivation. Not one respondent in the present study mentioned socioeconomic factors in explaining their risk judgement, and there was no evidence from examining the socioeconomic characteristics of the sample in relation to risk judgements that it was influential. Further, Study 3 found no relationship between the two in a large population sample. This suggests that area-level deprivation may be an inappropriate way of operationalising the "environment" factor. Future work may better capture the "environment" factor by asking questions related to the risk associated with things that are added to food. The present study found that "psychological factors" were represented by expressions of hope that one would not develop bowel cancer. Study 3 had no such measures and instead operationalised the psychological factor with a measure of state anxiety.

This qualitative study has therefore highlighted ways that the measurement of some of the Weinstein factors could be improved and this may lead to more of the variance in perceived risk being explained. However, "heredity" and "physical/physiological" factors were frequently mentioned explanations and these factors were well operationalised in Study 3. This leads one to conclude that even with better measures of "actions and behaviour patterns", "psychological factors" and "environment" a large amount of the variance in perceived risk may remain unexplained. This is an avenue for future work.

### *7.4.2. Differences between comparative optimists, comparative pessimists and those rating their risk as 'the same'*

Overall, comparative optimists were less likely to have a family history of cancer or to have other experience of cancer. They also felt healthier and mentioned more risk reducing health behaviours. Comparative pessimists were the opposite. They were more likely to have a family history and more experience of cancer, and to have symptoms.

In trying to understand the differences between those perceiving their risk of bowel cancer as below, the same or above average, it is worth considering how these three groups vary in the explanations they gave. It seems that actions and behaviour patterns provide few clues

in distinguishing between the three groups. Health behaviours are discussed in a biased way and mentioned as risk reducing by all three groups although one comparative pessimist mentioned smoking and drinking as increasing her risk. Risk reducing health behaviours were most often mentioned by comparative optimists but it is not possible to determine from the present analysis whether this reflects their healthier lifestyle or their ability to think of health behaviours as reasons. Psychological and environmental factors similarly do not appear to explain the differences between the three groups. The factors of 'chance' and 'don't know' were most frequently mentioned by those rating their risk as 'the same' and this may be reflecting the fact that this group do not have strong reasons to believe that they are at higher than average risk but at the same time they are not using actions and behaviour patterns and general health in the biased manner of the comparative optimists to justify their decision.

"Physical/physiology" went some way in distinguishing between the three risk judgment groups. Comparative optimists reported better health and fewer symptoms while comparative pessimists did not mention general health and indeed one mentioned having trouble with his bowels. It was interesting to note that five of the nine respondents rating their risk as 'the same' reported feeling more at risk of heart disease. This is an important point as it shows that other health concerns may be influential in risk judgments. One comparative optimist had an oesophageal problem and believed if he was going to get cancer it would be of the oesophagus and this may have been influential in thinking his risk for bowel cancer was below average. Another comparative optimist had high blood pressure and said he was more concerned about heart disease. However, only one comparative pessimist had a strong "physiological" reason for feeling at higher risk which was that she had a personal history of cancer.

The most useful factors in distinguishing between comparative optimists, pessimists and those seeing their risk as average are family history and experience. Comparative optimists were less likely to report a family history of cancer and if they did they had clear causal explanations as to why their family member had developed cancer which were not related to genetics or any exposure or behaviour of the respondent. Only two interviewees reported having members of their family who had had bowel cancer and both regarded their risk as higher than average. Amongst those rating their risk as 'the same' only one

respondent mentioned that having a family history of cancer increased her chances of developing bowel cancer. This respondent, while acknowledging her genetic predisposition, obviously did not believe that this factor put her at above average risk. Five other respondents in 'the same' category reported having a family history of cancer, but this did not lead them to perceive their risk as being any greater than their peers.

One factor which may account for the differential impact of family history and more generally the differences in risk beliefs is experience. The comparative optimists had little direct experience of cancer and the two who did, reported relatively positive accounts of people they knew with bowel cancer. The comparative pessimists talked about particularly traumatic and close experiences of bowel cancer. Among those rating their risk as 'the same' eight out of nine had no experience of someone close having bowel cancer.

Experience is well recognised as being influential in risk perception (Weinstein, 1987). It is also an example of an availability bias (Tversky & Kahneman, 1974). It is possible that adding experience to Weinstein's five factor framework would result in more of the variance being explained. It should be noted that in proposing the five factors, Weinstein (1984) was not attempting to 'explain' perceived risk, he was merely documenting the reasons that people gave for their risk judgments. It was perhaps naïve to presume in Study 3 that much of the variance would be explained by the five factors when other cognitive factors such as experience are known to influence risk perception.

### *7.4.3. Changes in risk judgements during the interview*

Four out of the five comparative optimists changed their risk estimate to 'the same' when asked to answer the comparative risk question at the end of the interview. These were the only respondents to change their risk judgement; all others rated their risk in exactly the same way as at the start of the interview. This finding is potentially very important as it suggests that people's risk perceptions may be amenable to change. Further, it indicates that having people talk about bowel cancer and discuss its causes, does not lead people to become overly concerned or worried about bowel cancer as not one respondent shifted from seeing their risk as 'the same' to 'higher'. These findings tentatively suggest that if

comparative optimists can be engaged in thinking about bowel cancer, they are less likely to have optimistically biased beliefs.

There are of course limitations to the study. Respondents represented only those who agreed to be interviewed. 27% of potential participants were not interested in being interviewed. Qualitative research is not concerned with making generalizations about the sample population unlike quantitative methods. However, as mentioned in Study 2 it is possible that a more 'realistic' sample was obtained than exists in the population as a whole. There was little evidence amongst the comparative optimists of 'unrealistic' beliefs and all five provided a variety of plausible reasons for their risk judgments.

The present study combined two different methods to explore people's perceptions of their bowel cancer risk. The first method, content analysis- something of a hybrid between quantitative and qualitative approaches, provided a useful technique for identifying the reasons respondents gave for their risk judgments. Thematic analysis was then used to explore in greater depth the influences on respondents' beliefs about their perceived risk. The findings broadly supported the five factor framework proposed by Weinstein (1984). However, in terms of trying to explain perceived risk, experience may be a useful addition to the model.

# CHAPTER 8

## Study 5: Weinstein's (1984) five factor framework re-visited

### 8.1. Introduction

Study 3 found that Weinstein's five factor framework (actions and behaviour patterns, heredity, physical/physiology, psychological attributes, and environmental factors) explained only 8% of the variance in comparative perceived risk when operationalised using data from the UK FS Trial. Study 3 was limited in that the measures available from the UK FS Trial data may not have fully captured the underlying construct of the factors. For example under the factor 'actions and behaviour patterns' only simple measures of smoking and exercise were available.

The qualitative interviews in Study 4 were helpful in better understanding people's reasons for their risk judgements, and why Study 3 failed to explain more of the variance in perceived risk for bowel cancer. Study 4 found that diet was a frequently mentioned reason, and this was not measured in Study 3. Furthermore, smoking and exercise (the measures representing the factor 'actions behaviour patterns' in Study 3) were rarely mentioned as reasons by the interviewees. There was no mention of area-level deprivation influencing people's perceived risk of developing bowel cancer, yet this was the measure used to operationalise the 'environment' factor in Study 3. The 'environmental' reasons given by interviewees in the qualitative study were related to things that are added to food (e.g. additives and preservatives). An additional factor that emerged during the interviews as being influential on perceptions of risk was the type and level of experience or exposure an individual had had to someone either with bowel cancer or some other form of cancer. Experience was not described as a factor by Weinstein (1984), but it has been found in the

literature (Weinstein, 1987; Tversky & Kahneman, 1974) to be influential in risk perception.

It was concluded from the literature that measuring perceived control may also be helpful in explaining more of the variance in perceived risk. People with a stronger sense of perceived control tend to have greater optimism compared to those with a weaker sense of control (Drake, 1987; Hoorens & Buunk, 1993). Being overweight is associated with increased risk for bowel cancer (Colditz et al., 2000), and so this measure was also included to explore its influence on perceived risk.

In designing Study 6, the intervention study, I decided to improve on the measurement of the five Weinstein factors to see whether more of the variance in perceived risk for bowel cancer could be explained. The aim of the present study was to determine whether more of the variance in perceived risk could be explained by better operationalising the five Weinstein factors. Only participants in the control group were included to make the results comparable with Study 3.

### *8.1.1. Hypothesis*

1. By using better measures to operationalise the five Weinstein (1984) factors, more variance in perceived risk will be explained than in Study 3.

## 8.2. Method

1056 questionnaires were mailed to adults aged 45-65 years from GP registers. The methods used in the present study are identical to those used for the control group in Study 6, see section 9.2.

*8.2.1 Materials*

*Perceived risk.* The perceived comparative risk question was, "Compared to others of the same sex and age, my chances of getting bowel cancer are: much below average; below average; average; above average; much above average; have had bowel cancer" as used by (Weinstein, 1987). Responses were scored by allocating -2 for "much below average", -1 for "below average", 0 for "average", +1 for "above average" and +2 for "much above average". While in Study 3 the response categories were recoded into a three-point scale, the present study will maintain the five point scale to retain as much information as possible within the data for the analyses.

*Demographic characteristics.* Age and gender were known from the lists provided by the GPs and allowed comparisons to be made between respondents and non-respondents on these characteristics. Simple items were use to assess ethnicity, "What is your ethnic group?" ("White; Mixed; Asian or Asian British; Black or Black British; Chinese; Other; do not wish to answer") and marital status, "What is your marital status?" ("Single; Married; Cohabiting/living with partner; Divorced/separated; Widowed").

*Operationalising Weinstein's (1984) five factors*

*"Actions and behaviour patterns".* These were operationalised with the following measures:

Smoking was assessed with the item, "Please tick the box that best describes your smoking habits: Never-smoker/non-smoker; Ex-smoker; Smoker".

Physical activity was assessed with two questions, one about vigorous activity and the other about moderate activity, "During the past 7 days, on how many days did you: Engage in vigorous activity that caused you to breathe much harder than normal and sweat (e.g. swimming, jogging, aerobics, football)?" and "Engage in moderate activity that caused you to breathe somewhat harder than normal (e.g. cycling, gardening, dancing, brisk walking)?" For each question participants were asked to write how many days per week they had engaged in that activity, and for how many minutes per day. "Don't know/not sure" was also a response option. For the purposes of analyses participants were categorised as either

meeting physical activity recommendations (e.g. 3 days of at least 20 minutes of vigorous activity or 5 days of at least 30 minutes of moderate activity; Department of Health, 2004) or not meeting the recommendations.

Three questions asked about fruit, vegetable and red meat consumption, "On a typical day how many servings of following would you eat?" The fruit item read, "Fruit (fresh, frozen or canned)? For example, one apple counts as one serving". The vegetable item read, "Vegetables (including salad, but excluding potatoes)? For example a handful of carrots counts as one serving". The red meat item asked, "Red meat (including beef, pork, lamb)? For example a chop counts as one serving".

Alcohol intake was measured with the question, "In a typical week how many units of alcohol would you consume? For example a unit is a small glass of wine or half a pint of lager". In all four cases an empty box was provided with the instruction, "Please enter the number of servings/units in the box".

*"Heredity"*. Family history of bowel cancer in first degree relatives was assessed with the question, "Have any members of your family (blood relatives, not relatives by marriage) had bowel cancer?" "Options were mother; father, son(s); daughter(s); sister(s); brother(s) with participants asked to indicate "yes; no; don't know; not applicable" for each relative. These responses were categorised as none, one, and two or more for initial analyses.

*"Physical/physiology"*. Bowel symptoms, subjective health and BMI were used to operationlise this factor. Bowel symptoms over the past three months were assessed with a list of 7 symptoms (constipation, haemorrhoids, diarrhoea, wind, pains in abdomen, incontinence, blood in stools). Symptom frequency was rated as "no; occasionally; frequently". A total symptoms score was calculated by totaling the number of symptoms that were experienced occasionally or frequently. The total symptoms score was divided into 3 groups for analyses: zero or one symptom; two or three symptoms; and four or more symptoms. Subjective health was assessed with the item, "Would you say that for someone of your age your own health in general is: excellent; good; fair; poor" (Health Survey for England, 1996). Body Mass Index (BMI) was calculated based on simple measures of height and weight. The height question asked, "How tall are you?" There was the option

of either providing the answer in feet and inches or in centimetres. The weight question asked, "How much do you weigh?" Again, there was the option of providing the answer in either stones and pounds or kilograms. BMI was calculated as weight in kgs/height in metres$^2$.

*"Psychological factors"*. This factor was operationlised with a measure of perceived control and state anxiety. Perceived control over bowel cancer was measured with the item, "There are things I can do to control whether I get bowel cancer or not". With the response options "strongly disagree, disagree, not sure, agree, strongly agree". State anxiety was recorded with the shortened, 6-item version of the Spielberger State Trait Anxiety Inventory (STAI; Spielberger, 1983; Marteau & Bekker, 1992). Respondents were asked to indicate on a four-point Likert type scale ranging from "not at all" to "very much" how they feel right now; calm, tense, upset, relaxed, content, worried. Internal reliability of the STAI was high with a Cronbach's $\alpha$=0.84.

*"Environment"*. To provide comparison with Study 3, Townsend Deprivation scores were included in the present study. Postcode data were used to link participants' area of residence to information from census enumeration districts (based on an average of around 460 residents) to index neighbourhood-level deprivation (Townsend Material Deprivation Index; Townsend et al., 1988) using data from the 1991 census (Crown Copyright, 1991).

The 'environment' factor was also measured with two attitudinal statements. "Environmental pollution may increase the risk of bowel cancer" and "The things that are added to food (e.g. additives and preservatives) may increase the risk of bowel cancer". The response options were "strongly disagree, disagree, not sure, agree, strongly agree".

*"Experience"*. Experience was operationlised with the question, "Have any of your close friends had bowel cancer?" Responses were "yes; no; don't know".

*8.2.2. Analysis of results*

All analyses were carried out using SPSS (Version 10.1). Linear trends in proportions across perceived risk categories were assess with SPSS linear-by-linear Chi square tests (a measure of linear associations between the row and column variables in cross-tabulation). Spearman's rhos were also used to describe the relationship between perceived risk and the five Weinstein factors, experience and demographic characteristics, to give an indication of the size of the association.

Multivariate ordinal regression was used to calculate a Pseudo R-squared (McFadden) to examine the amount of variance in perceived risk that could be explained by the framework.

## 8.3. Results

*8.3.1. Demographic characteristics*

This sample is the control group from Study 6 and details of the characteristics of the sample can be found in the results section of Study 6. Briefly, 648 people returned the questionnaire, representing a 61% response rate. More women (53%) than men (47%) returned the questionnaire, see Table 8.1. The mean age of the sample was 55 years. 98% of the sample were white and 68% were married. Respondents were significantly more affluent than the national average, with the mean Townsend score deviating significantly below zero which is the average score for England and Wales ($t(632)=-14.19$, $p<0.001$). The majority of respondents (70%) were in the most affluent group of the individual deprivation index with only 2% falling in the most deprived category.

**Table 8.1: Demographic characteristics of the sample**

| | n=648 | % or Mean (sd) |
|---|---|---|
| Gender | | |
| Female | 345 | 53.2% |
| Male | 303 | 46.8% |
| Age Mean (sd) | 648 | *M*=54.8 (5.75) |
| Ethnicity N (%) | | |
| White | 630 | 98.0% |
| Non-white | 13 | 2.0% |
| Marital status N (%) | | |
| Married | 440 | 68.4% |
| Cohabiting | 51 | 7.9% |
| Divorced/separated | 82 | 12.8% |
| Widowed | 17 | 2.6% |
| Single | 53 | 8.2% |
| Townsend score Mean (sd) | 633 | *M*=-1.44 (2.56) |
| Individual deprivation score | | |
| 0 (affluent) | 434 | 69.8% |
| 1 | 134 | 21.5% |
| 2 | 41 | 6.6% |
| 3 (deprived) | 13 | 2.1% |

### *8.3.2. Associations between perceived risk and Weinstein's five factors*

*Demographics.* Gender, age and martial status were not significantly related to perceived risk in the present sample, see Table 8.2. 46% of non-white respondents viewed their risk as lower than average compared with 24% of white respondents.

*"Heredity".* Respondents with a family history of bowel cancer (41%) were almost seven times more likely to judge their risk as higher than average compared with those without a family history (6%), see Table 8.2.

*Actions and behaviour patterns.* Smokers (18%) were also more likely to see their risk as higher compared with non-smokers (8%). Respondents meeting physical activity recommendations were significantly more likely to view their risk as lower than average,

see Table 8.2. Respondents consuming more red meat and fewer fruits and vegetables were more likely to see their risk as higher.

*"Physiology"*. Those with more bowel symptoms, poorer subjective and greater BMI were significantly more likely to report their risk as being higher than average, see Table 8.2.

*"Psychological factors"*. Respondents who were more anxious and those who did not believe there were things they could do to control getting bowel cancer were also significantly more likely to perceive their risk as higher.

*"Environment"*. Townsend scores and the belief that things added to food increased bowel cancer risk were not significantly associated with perceived risk, see Table 8.2. However, believing that there were things in the environment which increased risk was significantly related to greater perceived risk.

*"Experience"*. The experience of having a close friend with bowel cancer was not significantly related to personal risk perception, see Table 8.2.

**Table 8.2: Associations between perceived risk and Weinstein's five factors**

| | Perceived risk | | | Significance |
|---|---|---|---|---|
| | Lower | The same | Higher | |
| All respondents (n=648) | 24.6 | 66.2 | 9.1 | |
| *Demographic factors* | | | | |
| Gender % | | | | |
| Female (n=338) | 28.1 | 62.7 | 9.2 | |
| Male (n=298) | 21.1 | 69.8 | 9.1 | $\chi^2(2, 636)=4.3$, p=0.117 |
| Age % | | | | |
| 45-55 years (n=366) | 25.7 | 63.1 | 11.2 | |
| 56-66 years (n=270) | 23.7 | 70.0 | 6.3 | $\chi^2(1, 636)=0.4$, p=0.516 |
| Ethnicity % | | | | |
| White (n=618) | 24.4 | 66.3 | 9.2 | |
| Non white (n=13) | 46.2 | 53.8 | - | $\chi^2(1,631)=3.9$, p=0.049 |
| Marital status % | | | | |
| Married (n=435) | 26.0 | 65.1 | 9.0 | |
| Not married (n=196) | 22.4 | 68.4 | 9.2 | $\chi^2(1, 631)=0.6$, p=0.437 |
| *"Heredity"* | | | | |
| Family history (FDR only) % | | | | |
| 0 (n=585) | 26.2 | 67.5 | 6.3 | |
| 1+ (n=51) | 9.8 | 49.0 | 41.2 | $\chi^2(1, 636)=39.0$, p<0.001 |
| *"Actions and behaviour patterns"* | | | | |
| Smoking % | | | | |
| Smoker (n=85) | 17.6 | 64.7 | 17.6 | |
| Non smoker/ex-smoker (n=545) | 25.7 | 66.4 | 7.9 | $\chi^2(1, 630)=7.4$, p=0.007 |
| Meeting physical activity recommendations % | | | | |
| Yes (n=180) | 32.2 | 58.3 | 9.4 | |
| No (n=456) | 21.9 | 69.1 | 9.0 | $\chi^2(1, 636)=4.0$, p=0.047 |

Table 8.2 continued

| | Perceived risk | | | Significance |
|---|---|---|---|---|
| | Lower | The same | Higher | |
| Red meat consumption *M* (sd) | 0.65 (0.50) | 0.90 (0.60) | 0.95 (0.72) | F(1, 616)=18.8, p<0.001 |
| Vegetable consumption *M* (sd) | 2.93 (1.46) | 2.54 (1.24) | 2.54 (1.51) | F(1, 629)=7.7, p=0.006 |
| Fruit consumption *M* (sd) | 2.43 (1.39) | 2.02 (1.31) | 2.15 (1.5) | F(1, 625)=5.8, p=0.016 |
| Alcohol consumption *M* (sd) | 7.77 (8.31) | 8.64 (9.61) | 7.50 (10.26) | F(1, 622)=0.09, p=0.796 |
| | | | | |
| *"Physiology"* | | | | |
| Bowel symptoms % | | | | |
| 0, 1 (n=261) | 30.3 | 65.1 | 4.6 | |
| 2, 3 (n=244) | 22.5 | 68.4 | 9.0 | |
| 4+ (n=131) | 18.3 | 63.4 | 18.3 | $\chi^2$(1, 636)=18.1, p<0.001 |
| | | | | |
| Subjective health % | | | | |
| Excellent (n=129) | 45.7 | 47.3 | 7.0 | |
| Good (n=391) | 20.7 | 70.6 | 8.7 | |
| Fair (n=101) | 14.9 | 74.3 | 10.9 | |
| Poor (n=12) | 8.3 | 58.3 | 33.3 | $\chi^2$(1, 633)=30.2, p<0.001 |
| | | | | |
| BMI *M* (sd) | 25.5 (4.50) | 26.6 (4.56) | 27.5 (6.23) | F(1, 622)=9.72, p=0.002 |
| | | | | |
| *"Psychological factors"* | | | | |
| Anxiety % | | | | |
| Low (n=280) | 29.3 | 66.1 | 4.6 | |
| Medium (n=180) | 23.9 | 67.2 | 8.9 | |
| High (n=174) | 19.0 | 64.4 | 16.7 | $\chi^2$(1, 634)=16.9, p<0.001 |
| | | | | |
| Things you can do to control bowel cancer % | | | | |
| Disagree (n=37) | 10.8 | 75.7 | 13.5 | |
| Not sure (n=232) | 17.2 | 72.4 | 10.3 | |
| Agree (n=360) | 30.8 | 61.1 | 8.1 | $\chi^2$(1, 629)=15.1, p<0.001 |

Table 8.2 continued

| | Perceived risk | | | Significance |
|---|---|---|---|---|
| | Lower | The same | Higher | Lower |
| *"Environment"* | | | | |
| Townsend score *M* (sd) | -1.01 (2.52) | -1.64 (2.54) | -1.30(2.67) | F(1, 621)=2.7, p=0.100 |
| Things in environment increase risk of bowel cancer % | | | | |
| Disagree (n=56) | 23.2 | 66.1 | 10.7 | |
| Not sure (n=419) | 22.4 | 67.8 | 9.8 | |
| Agree (n=156) | 32.1 | 60.9 | 7.1 | $\chi^2$(1, 631)=4.3, p=0.038 |
| Things added to food increase risk of bowel cancer % | | | | |
| Disagree (n=21) | 33.3 | 66.7 | - | |
| Not sure (n=252) | 22.2 | 69.8 | 7.9 | |
| Agree (n=359) | 26.2 | 63.2 | 10.6 | $\chi^2$(1, 632)=0.2, p=0.691 |
| *"Experience"* | | | | |
| Close friends with bowel cancer % | | | | |
| Yes (n=133) | 23.3 | 65.4 | 11.3 | |
| No (n=444) | 25.9 | 65.8 | 8.3 | |
| Don't know (n=55) | 20.0 | 70.9 | 9.1 | $\chi^2$(1, 632)=0.1, p=0.754 |

### *8.3.3. Correlations between perceived risk and Weinstein's five factors*

At least one measure of each of Weinstein's factors showed a significant association with perceived risk of developing bowel cancer. Subjective health had the strongest correlation, followed by family history, and red meat consumption, see Table 8.3. All of the "actions and behaviour patterns" measures were significantly correlated with perceived risk, with the exception of alcohol consumption. In the "physical/physiology" factor, bowel symptoms, subjective health and BMI were all significantly associated with perceived risk. As in Study 3, state anxiety was positively correlated with perceived risk and the new measure for this study, perceived control was significantly negatively correlated indicating, as predicted, that greater perceived control was associated with greater comparative optimism. In the "environmental" factor both the Townsend score and the attitudinal

measure of things added to food increasing risk were not significantly correlated. However, the attitudinal measure that environmental pollution could increase the risk of bowel cancer was slightly negatively related to perceived risk, suggesting that those that believed this more strongly were more comparatively optimistic. Surprisingly, the experience of having a close friend with bowel cancer was not significantly related to perceived risk.

Among the demographic factors, only ethnicity was significantly negatively related to perceived risk. This suggests that non-white participants were more likely to be comparatively optimistic, as was found in Study 3.

**Table 8.3: Relationship between perceived risk and Weinstein's five factors, experience and demographic characteristics (higher scores=higher perceived risk)**

| | Perceived risk (Spearman's rho) |
|---|---|
| *"Heredity"* | |
| Family history (FDR only) | 0.230** |
| *"Actions and behaviour patterns"* | |
| Smoking | 0.135** |
| Meeting physical activity recommendations | 0.088* |
| Red meat consumption | 0.182** |
| Vegetable consumption | -0.118** |
| Fruit consumption | -0.110** |
| Alcohol consumption | -0.019 |
| *"Physiology"* | |
| Bowel symptoms | 0.171** |
| Subjective health | 0.238** |
| BMI | 0.116** |
| *"Psychological factors"* | |
| Anxiety | 0.169** |
| Perceived control | -0.166** |
| *"Environment"* | |
| Townsend score | -0.078 |
| Environmental pollution | -0.082* |
| Things added to food | -0.003 |
| *"Experience"* | -0.047 |
| *Demographic factors* | |
| Age | -0.043 |
| Gender | 0.062 |
| Marital status | 0.013 |
| Ethnicity | -0.085* |

*significant at $p<0.05$
**significant at $p<0.01$

*8.3.4. Do Weinstein's five factors explain the majority of the variance in perceived risk?*

Only those variables found to be significantly related to perceived risk of bowel cancer were entered into the multivariate ordinal regression to calculate Pseudo R squared. Family history, smoking, subjective health, BMI and anxiety remained significant in multivariate analyses. The model was highly significant $\chi^2(73, 584)=210.4$, and the proportional reduction in $\chi^2$ compared to the 'constant only' model (Pseudo R squared) was 18.5%. This means that 18.5% of the variance in perceived risk was explained by Weinstein's five factors and the demographic factors combined.

## 8.4. Discussion

The aim of this study was to determine whether Weinstein's (1984) five factor framework (heredity, physiology, environment, actions and behaviour patterns, and psychological factors) could explain more of the variance in perceived risk if better measures were used to operationalise the factors than in Study 3. The control group from Study 6 provided the opportunity to retest Weinstein's framework using a broader range of variables to capture each of the five factors.

Family history and subjective health showed the strongest associations with perceived risk of developing bowel cancer. The relationship between bowel symptoms and perceived risk was significant (Spearman's rho=0.171, $p<0.01$) but was not quite as strong as in Study 3 (Spearman's rho=0.222, $p<0.001$). The new measures of red meat and perceived control were also amongst the variables showing the strongest associations with perceived risk. However, overall the correlations in this study were low, and would only be regarded as 'small' using Cohen's (1992) estimation of effect sizes referred to in Study 3.

It was surprising to find that the additional measure of 'experience' was not significantly related to perceived risk. From the interviews conducted in Study 4 and from the literature on risk perception (Weinstein, 1987; Tversky & Kahneman, 1979), it appeared that experience may be influential in guiding risk judgements. In a study examining perceptions of risk for breast and colon cancer, heart disease, and diabetes, having a friend with the

disease was found to increase perceptions of risk in women but not in men (Montgomery et al., 2003). I repeated the analyses for men and women separately, but experience was not significantly related to perceived risk for men or women. It is possible that asking participants if they had any close friends with bowel cancer was more of a proxy measure and was not sensitive enough to capture this. A measure is needed that taps more into the emotional level of the experience as that was what came out as being important in the interviews in Study 4. If such a measure could be developed it may be possible to begin to untangle the relationship between family history and perceived risk by separating out beliefs about genetic inheritance from the emotional and cognitive impact of having someone in the family with bowel cancer.

To assess the total amount of comparative perceived risk explained by Weinstein's five factors, a pseudo R-squared was calculated. 18.5% of the variance was explained. This result represents an improvement on the 8% of variance explained in Study 3. It suggests that using a broader range of variables to measure each of the factors was successful in explaining more of the variance in perceived risk.

Despite the increase in variance explained, a good deal remained unexplained. One possible explanation is that people do not have access to the processes involved in making a risk judgments. When they are asked to give reasons for their estimate, they come up with the five factors (Weinstein, 1984; Study 4), but the present study suggests that these are not the main factors governing their risk judgments. Throughout this thesis, I have concentrated on understanding the rational reasons for risk estimates that are accessible via self-report. However, future work may benefit from more subtle approaches that tap into unconscious processes. Slovic (2000) developed Epstein's (1994) distinction between rational and experiential thought systems, to suggest that the rational system is assumed to base decisions on a conscious appraisal of the situation while the experiential system uses associative connections that are more likely to be sub-conscious and automatic. Windschitl (2003) believes this conceptualization fits with some individual's experiences of feeling uneasy about a hazard but knowing at a 'rational' level that the hazard is unlikely to occur e.g. flying vs. driving. It may be the case that the experiential system dominates in risk perception and if risk perception is to be fully understood an appreciation of both the cognitive/rational and the experiential/affective factors may be required.

An alternative or complementary explanation for the large amount of unexplained variance in perceived risk is that people weight their reasons for their risk estimates in such an idiosyncratic manner that the correlation with perceived risk for the group is weak (Weinstein, 1984). Further, any one risk factor may only be salient for a few people (Weinstein, 1984). Future work, using qualitative methodology, might usefully explore this explanation by asking participants to talk explicitly about each factor and to describe how important they feel each factor is in their overall estimation of risk.

This study has shown that with better measures more of the variance in perceived risk for bowel cancer can be explained using Weinstein's (1984) five factor framework. 10% more variance was explained compared to Study 3. However, the vast majority of perceived risk remained unexplained and consideration of the experiential as well as the rational thought processes may prove useful in understanding how people perceive their risk.

# CHAPTER 9

## Study 6: Can perceptions of risk for bowel cancer be changed? A randomised trial of the impact of giving bowel cancer risk information on perceptions of risk, knowledge and interest in bowel screening

### 9.1. Introduction

The aim of this study was to determine whether giving people simple, accurate information about bowel cancer risk would alert them to their personal risk of developing it, and thereby increase their interest in attending screening when it becomes available. It builds on the conclusions of the previous set of studies which have identified the subgroups most likely to show comparative optimism and examined people's explanations for their risk judgements.

Findings from Study 1, examining the correlates of perceived bowel cancer risk, showed that some subgroups of the population are more likely to perceive themselves as low risk for bowel cancer than others. Being male and older were both associated with more comparatively optimistic beliefs. These findings are particularly worrying because both factors have consistently been linked to higher risk of colorectal cancer (Quinn et al., 2001), indicating that the optimism bias is opposite to the true risk. This suggests the need for future risk communications to address misperceptions concerning age and gender.

Data from the UK FS Trial also allowed the examination of associations between health-related factors and perceived risk. Study 1 found that having no family history of bowel cancer, few bowel symptoms and good subjective health were all related to more optimistic beliefs, confirming other work which shows these to be frequently cited influences on risk judgements (Helzlsouer et al., 1994; Lipkus, Rimer, & Strigo, 1996; Weitzman et al., 2001). These findings are also worrying. The problem with individuals 'using' family

history of bowel cancer in judging their own risk is that the familial link for the majority of bowel malignancies is small (Lichtenstein et al., 2000), so while a strong family history might be a cause for greater vigilance, the absence of a family history is no basis for complacency. The finding that bowel symptoms and subjective health strongly influence risk perception is also of concern given the pathogenesis of bowel cancer is often asymptomatic until an advanced stage (Weitzman et al., 2001), so lack of symptoms or feeling well should not lead people to believe themselves to be at low risk. Risk communications about bowel cancer therefore also need to tackle misunderstandings both of the familial link and the 'silent' status of bowel cancer.

Weinstein's (1984) five factors provided a useful heuristic in thinking about the factors that could be used to change perceptions of risk. Results from Studies 1 and 3 showed the major correlates of perceived risk could be conceptualised within Weinstein's framework. Furthermore, these factors were confirmed as being important influences on people's risk estimates in the qualitative Study 4 and in the quantitative Study 5.

Changing people's perceived risk is not necessarily easy, indeed some apparently well-founded interventions entirely failed to reduce optimistic beliefs (e.g. Weinstein & Klein, 1995). However, the results from the qualitative interviews in Study 4 suggested that making comparative optimists think about their reasons for their risk judgements and discuss bowel cancer, reduced optimistic beliefs in four out of five of them. These results are clearly very tentative because of the small number of participants involved, however they do suggest that risk perceptions are amenable to change if people are made to think about the factors influencing their risk. In the situation where there is a relatively new screening programme to be launched – as is the case for bowel cancer in the UK – it could be argued that it is particularly important for people to understand that anyone could be at risk and that all should consider taking advantage of the opportunity for screening. This is especially true for FS screening, which is designed not merely to detect cancer before there are clinical manifestations, but to detect and remove the pre-cancerous stage of the disease and thereby reduce the risk. A screened person would indeed be less at risk than the average non-screened person; possibly reducing their risk by half if polyps are removed (Selby, Friedman, Quesenberry, & Weiss, 1992). To deliver population based screening successfully, we need to start understanding the process of public education and learning

how we can provide people with the appropriate information from which to learn about cancer risks and consider the option of screening. If people are unrealistically optimistic because of false beliefs about risk factors, then giving them correct information should achieve some reduction in their optimistic bias.

A risk message may be regarded in terms of a 'threat' which would impact not only on cognitions about the event occurring, but also on emotional response. The present study will therefore assess the impact of the risk message on worry about bowel cancer and general anxiety, to assess whether attempting to reduce optimistic beliefs has an adverse effect on emotional wellbeing. One way of allaying any detrimental effects is to tell people that an effective screening programme is going to be available in the near future. In the Fear-drive Model (Hovland et al., 1953) it is proposed that a threatening message (e.g. a leaflet containing risk factors for bowel cancer) can induce fear in the receiver, but if behavioural advice is given at the same time then the threat is diminished. The present study was designed to explore the differential impact of providing risk information in parallel with screening information. It therefore explored the impact of risk information on both perceived risk and worry, as well as comparing the impact of risk factor information alone versus when combined with behavioural advice in the form of screening information.

### *9.1.1 The relationship between absolute and comparative risk perception*

In carrying out the qualitative interviews in Study 4, it was not always apparent that in answering the comparative perceived risk question participants were fully engaged in a social comparison process. In one sense, social comparison was implicit in their explanations e.g. "*I'm quite a healthy eater*" (012) which may be interpreted as suggesting that other people are not healthy eaters. However, it was my impression that not all participants compared themselves to others of the same sex and age as instructed, and answered the question in a more absolute manner. This raised the question of whether comparative and absolute measures were different constructs or whether there was a degree of overlap.

Klein (2003) notes that absolute and comparative risk measures need not be related; someone may regard their absolute risk as high (or low) but still perceive their comparative

risk to be lower (or higher) than others of the same age. An example of this would be a smoker who realises that they have an increased absolute risk of developing lung cancer but they remain optimistically biased when they compare themselves to other smokers (Lee, 1989; McKenna et al., 1993). Indeed, Klein (2003) goes on to add that people may hold a comparative risk estimate without having any sense of their level of absolute risk.

In his thoughtful paper, Klein (2003) poses the question of whether comparative risk measures are truly 'comparative' or whether many people fail to consider 'others of the same sex and age', as instructed by the question, and instead answer such questions in an 'absolute' manner. In a similar vein, it may be argued that absolute measures are comparative measures 'in disguise' and people have no way of judging their risk without a comparative referent. Klein (2003) concludes that because we know comparative risk judgements remain correlated to worry and behavioural intentions when absolute risk perceptions are controlled (Lipkus, Kuchibhatla, McBride, Bosworth, Pollak et al., 2000; Klein, 2002), and that absolute risk perceptions predict behavioural intentions when comparative risk estimates are controlled (Lipkus et al. 2000), the two types of risk perception seem psychologically and statistically separable.

Despite this distinction, it seems likely that for some threats comparative and absolute perceived risk may be related. Few studies have reported the correlation between the two, however Lipkus et al. (2000) reported a strong and significant association (Spearman's $rho=0.60$ $p<0.001$) between perceived absolute and comparative lifetime breast cancer risk. In a study comparing absolute and comparative perceived risk for bowel cancer in patients attending a familial colorectal cancer clinic, Collins, Halliday, Warren, and Williamson (2000) found the two measures were significantly related although the correlation was not reported. This suggests that while absolute and comparative perceived risk may be independent contributors to perceptions of worry, there is a significant amount of overlap between the two measures.

*9.1.2. Knowledge and dispositional optimism*

Knowledge of bowel cancer is very limited in the UK, with 58% of respondents in a population representative sample unable to list any bowel cancer risk factors (McCaffery et al., 2003). Furthermore, suboptimal knowledge and awareness of bowel cancer risk factors have been cited as barriers to screening (Yood et al., 2003). With the introduction of bowel screening in 2006 it is important that people become better informed about the disease so that they are able to make an informed choice about whether or not to attend screening. However, increasing people's knowledge is not easy. Leaflets have been the preferred medium for conveying information about cancer because they are cheap and easily disseminable. Unfortunately, studies of health literacy suggest that people may not be equipped with sufficient skills to be able to understand what is contained in an information leaflet (Davis, Williams, Marin, Parker, & Glass, 2002). It is estimated that around 23% of British adults are functionally illiterate (Adult Literacy in Britain, ONS, 1997). A study of written information given to patients and families in palliative care units found that most leaflets could be understood by fewer than 40% of the population (Payne, Large, Jarret, & Turner, 2000). However, there was no alternative to leaflets for this study, but great efforts were made to ensure that the information produced for this study was easily understood by the intended audience.

There is some evidence to suggest that individuals high on dispositional optimism are often very vigilant to information about future health risks, and this vigilance may help them to offset their risk before an adverse condition develops. Therefore the present study will also examine whether people high in dispositional optimism have higher knowledge of risk bowel cancer risk factors.

This is the first study of its kind to assess the effectiveness of an intervention to reduce optimistic beliefs about bowel cancer in a population sample using an adequately powered design. If information leaflets are successful in reducing those with no family history and few bowel symptoms' unrealistically optimistic beliefs and increases men and older people's perceived bowel cancer risk, then this provides a comparatively simple and cost-effective means of encouraging people to attend bowel screening when it is introduced.

### *9.1.3. Hypotheses*

The present study has several hypotheses.

1. Knowledge will be low, but higher in those with more education and more dispositional optimism
2. Giving people simple information about bowel cancer risk will increase their knowledge of risk factors
3. Giving people simple information about bowel cancer risk will reduce the optimistic bias associated with lack of symptoms or family history, and will increase perceptions of risk in men and older people
4. The combination of giving people risk factor and screening information will minimise any adverse effects in terms of worry and anxiety
5. Giving people simple information about bowel cancer risk will increase interest in attending for screening and readiness to seek medical attention for symptoms

## 9.2. Methods

### *9.2.1. Design*

The present study was a between-groups design assessing the impact of mailed risk factor information with or without screening information on perceptions of risk, knowledge and intentions to attend screening. Participants were randomized to one of the following three groups:

Group 1: Control group – no information

Group 2: Information leaflet on risk factors for bowel cancer

Group 3: Information leaflet on risk factors for bowel cancer plus information on bowel cancer screening tests.

There was a single assessment point because repeated administration of the questionnaire was judged to be unacceptable to participants.

### *9.2.2. Power analysis*

The power analysis was carried out using the programme Power and Precision 2, to determine the sample size needed to remove optimism bias. The effect size was calculated based on the 5-point comparative risk question asked in Leeds and Harrow in the UK FS Trial. The mean for these two centres was $M$=-0.13 $SD$=0.74, indicating an optimism bias with the mean deviating significantly from the mid-point ($t(5219)=-13.0$, $p<0.001$). The aim was to remove the comparative optimism bias so that the mean for the sample would be $M$=0.00 indicating that as a group, perceived risk of bowel cancer was the same as average. To achieve this in a randomised controlled trial, a difference in perceived risk $M$=0.13 between the control and intervention groups would be required so that the mean for the intervention groups would be $M$=0.00. With $\alpha$=0.05 and $\beta$=0.80, it was calculated that a sample of n=498 per group would be required to detect a difference in perceived risk of 0.13. This would allow the study to be powered to detect a small effect.

With an expected response rate of 50%, 3,000 people were contacted in order to yield a sample of 1,500 people (n=500 per group), which would provide adequate power for the planned statistical analyses; one-sample t-tests, Chi square tests, ANOVAs.

### *9.2.3. Participants*

Participants (N=3,185[25]) were men and women aged between 45 and 66 years registered with two General Practitioner (GP) surgeries in Exeter. Lists of names, addresses, gender and dates of birth were obtained directly from the GP surgeries. GPs were asked to exclude participants who had been diagnosed with cancer, and any 'vulnerable' participants they judged inappropriate for the study (e.g. very ill, recently bereaved, learning difficulties). This led to the exclusion of 6% of participants in one practice and 4% in the other. Having GPs exclude 'vulnerable' patients may have led to a slight bias in the sample because

[25] The number of participants was slightly greater than that required for statistical power. The GPs supplied more names and addresses than requested and since they had gone to the effort of checking the lists, I decided to include them in the sample.

although they were told the characteristics of people to exclude, I had no real control over who they thought was appropriate for the study. This is a concern but it was a pre-condition made by the GP surgeries in agreeing to participate in the study and seems unavoidable. To estimate the extent of the bias, I could have asked GPs to record the reason for each exclusion, but given their demanding workload this was not feasible.

### *9.2.4. Procedure*

Participants were randomised to groups by simple random allocation using Minitab. People living in the same household were randomised to the same condition. Participants in all three groups received letters signed by their GP informing them that their General Practice was working with University College London and Peninsula Medical School to look at people's views about bowel cancer because screening was going to be introduced in the UK in the next couple of years (see Appendix 9). The letter stressed that participants did not have to take part in the study unless they wanted to. Participants were told that they would not be provided with feedback on their responses to the questions, and that they should contact their GP if they were concerned about their bowel symptoms. The letter told participants that they should contact me if they wanted to find out more about the study. The letter referred participants to the information sheet for more details about the study (see Appendix 10). The information sheet outlined the purpose of the study, why they had been chosen, what the study would involve, confidentiality, reiterated the point in the letter that they did not have to take part unless they wanted to, and concluded that they should contact me if they had further questions about the study (telephone number, e-mail address and postal address were all supplied). Participants were invited to take part in the study by completing the enclosed questionnaire and returning it in the freepost envelope provided. Non-responders were sent a reminder questionnaire after two weeks (see reminder letter Appendix 11). The questionnaire was a seven page instrument which took a maximum of 15 minutes to complete (see Appendix 12). The questionnaire included items on demographics, health behaviours, beliefs about bowel cancer, bowel symptoms, perceived risk for various cancers, family history of cancer, experience of friends with cancer and psychological wellbeing. Ethical approval was obtained from the Chairman of the North and East Devon LREC (see Appendix 13). Research Governance approval was obtained from Exeter PCT (see Appendix 14).

*9.2.5. Intervention*

The intervention used for those given risk factor information and risk factor and screening information was an A5 four-page leaflet (an A4 sheet folded in half presenting four sides of information, see Appendix 15), as this provided an inexpensive way of communicating bowel cancer information to a large number of people. The features common to both intervention groups will be described first and the additional information provided in Group 3 will follow later.

The leaflet had the title "Bowel cancer: The facts" to be comparable with other information leaflets available for cancer (Department of Health, 2002). The contents of the leaflet addressed the comparative optimism biases observed in Study 1 for various demographic and health-related factors. Therefore the four key messages were:

1. Older people are at higher risk of getting bowel cancer
2. Men are at slightly higher risk of developing bowel cancer than women
3. The absence of a family history does not mean low risk
4. Even people without any symptoms may still be at risk
5. People with a less healthy lifestyle are at higher risk.

Information was also included on the prevalence of bowel cancer in the UK, that it is the second most common cause of cancer death, and that it develops from polyps. In addition, a list of the symptoms of bowel cancer was provided along with the advice that people should contact their doctor if they noticed any symptoms. If participants had any questions about the information in the leaflet they were asked to telephone or e-mail me.

Participants randomised to receive additional information about bowel screening were also given information on the two types of bowel screening the Government is considering introducing for men and women around the age of 60 years. The first was the faecal occult blood test (FOBT) described as examining a small sample of stool/bowel motion for early signs of cancer. The second was the flexi-scope test described as involving an experienced nurse inserting a thin tube into the back passage and painlessly removing polyps which helps to prevent bowel cancer (see Appendix 15).

*Developing the leaflet.* Efforts were made to make the leaflet as user-friendly and accessible as possible to the population. The recommendations of the NHS Toolkit for Providing Patient Information (2000), Centre for Health Information Quality (2002), Plain English Campaign, and O'Donnell & Entwistle (1999) were followed. These provide practical advice on presenting written information to the public. The advice of three experts in leaflet design was also sought in developing the format of the leaflet.

The leaflet used simple sentences to convey the information and was as brief as possible (word count: n=382 for risk factor information group, and n=503 for risk factor and screening information group). The Flesch Reading Ease formula was employed to assess the readability of the leaflet. The score obtained was 75.5[26] (scores between 60-70 are considered acceptable with higher scores indicating greater readability, Vahabi & Ferris, 1995). The Flesch-Kincaid Grade Level was 4.9 suggesting that a child in Grade 5 (of the US education system, so around the age of 10 years) should understand the leaflet. Two bar charts/histograms displayed the relationship between age and bowel cancer mortality, and gender and bowel cancer mortality. Studies have shown that bar charts are useful in conveying risk information (Stone, Yates, & Parker, 1997; Likpus and Holland, 1999; Berry, 2004), and may be preferable to more elaborate formats such as figures, survival curves and pie charts (Edwards, Elwyn, & Mulley, 2002).

The target population were involved at all stages of the leaflet development process. The survey of older adults in Study 1 revealed which subgroups of the population were likely to see themselves as at low risk for bowel cancer. The interviews with older adults in Study 4 further revealed gaps in people's knowledge about the causes of bowel cancer. These findings provided the impetus for communicating risk factor information.

The acceptability of the leaflet was assessed by having five people aged 60-64 years read it and provide feedback[27]. Most found it very informative and commented on the fact that they had not been aware of some of the risk factors (e.g. *"... if you are smoking you are at higher risk of getting bowel cancer. Amazing"* male aged 60 years (016); *"I think these*

[26] Despite Group 3 containing additional information on screening methods, the Flesch Reading Ease score and Flesch-Kincaid Grade Level were exactly the same for the leaflets used in Group 2 and Group 3.
[27] These were the last five people interviewed for Study 4. At the end of the interview they were shown the leaflet and asked for comments.

*diagrams are good, yeah, because you get a bit blasé.....For people who think it's never going to happen to them, you can see just at a quick glance"* female, aged 63 years (017); *"I wouldn't have known any of this"* female aged 62 years (019)). Their comments and suggestions were incorporated into the final leaflet design.

To ensure that the leaflet resulted in an increase in awareness, the leaflet was piloted on a further six lay people (aged 48-59 years) with their knowledge assessed, using the same questions as contained within the questionnaire, before and after reading the leaflet. For each knowledge question the mean score after reading the leaflet was higher than before. After reading the leaflet people were significantly more likely to agree that men are at higher risk ($F(1, 5)=45.0$, $p=0.001$), that exercise reduces risk ($F(1, 5)=7.35$, $p=0.042$), and that smoking increases risk ($F(1, 5)=14.4$, $p=0.13$). The other knowledge items (listed under the materials section following) were not significantly higher after reading the leaflet but this was attributed to the small sample size. The pattern of results suggested that the leaflet was having the desired effect of increasing knowledge of risk factors.

### *9.2.6. Piloting the questionnaire*

The questionnaire was the same in all three groups. It was broadly similar to the instrument used in the UK FS Trial (completed by ~ N=40,000) and so it was felt that the questionnaire did not need to be piloted widely. The questionnaire used in the current study asked additional questions about absolute perceived risk, family history and experience of close friends having bowel, breast, prostate and other types of cancer, beliefs/knowledge of bowel cancer, more detailed health behaviour questions, and items on seeking medical attention for bowel symptoms. The questionnaire was piloted on four adults aged around 60 years who all found it easy to answer, and did not find it distressing in anyway.

### *9.2.7. Materials*

A copy of the questionnaire used in the two intervention groups can be found in Appendix 12. The questionnaire used in the control group was identical but did not contain the instruction on the first page to read the leaflet before completing the questionnaire.

*Manipulation check.* Participants in the two intervention groups were instructed on the first page of the questionnaire to, "PLEASE READ THE ENCLOSED LEAFLET "Bowel Cancer: The facts" BEFORE FILLING OUT THE QUESTIONNAIRE". They were then asked, "Have you read the leaflet "Bowel Cancer: The facts"? ("yes; no").

*Perceived risk.* Two measures of perceived risk were used. Because a main aim of the study was to reduce optimistic bias amongst those without a family history and few bowel symptoms, a comparative measure of perceived risk was used. The perceived comparative risk question was, "Compared to others of the same sex and age, my chances of getting bowel cancer are: much below average; below average; average; above average; much above average; have had bowel cancer" as used by (Weinstein, 1987). Responses were scored by allocating -2 for "much below average", -1 for "below average", 0 for "average", +1 for "above average" and +2 for "much above average". This means that negative scores represent an optimistic bias while a positive number represents a pessimistic bias. To assist in the interpretation of results in some instances responses were recoded into a three point scale i.e. "much below average" and "below average" were recoded as "below average" and "above average" and "much above average" were recoded as "above average".

A second aim of the study was to specifically increase perceptions of risk in men and older people. The comparative risk question was therefore not suitable for detecting differences in men and older people because the question asks people to compare themselves to others of the same sex and age, and so it is not appropriate to use the comparative measure for this purpose. Perceived risk was therefore also assessed using an absolute measure, "As a percentage what do you think your chances are of getting bowel cancer? From 0% to 100% where 0 means you definitely won't be diagnosed with cancer and 100 means you definitely will be diagnosed with cancer". A blank space was provided for participants to enter their estimated number. This approach was taken because it seems probable that providing a range of responses from 0 to 100%, at 10% intervals, encourages people to overestimate their risk. An alternative is to use the Magnifier scale (Woloshin, Schwartz, Byram, Fischhoff, & Welch, 2000) which is a scale from 0-100% with the area from 0 to 1% 'magnified' with a magnifying glass to show small probabilities (e.g. 0.001%). However, bowel cancer is not such a rare occurrence that this would be helpful. One could magnify the area from 0-10% as the population risk in the UK is about 5% but doing so

may provide too much of a 'clue' to people that this is where their risk will most likely fall. It was therefore decide that providing a blank space was the most appropriate strategy for measuring absolute risk.

*Demographic characteristics.* Age and gender were known from the lists provided by the GPs and Townsend scores were also available for each patients' postcode. This allowed comparisons to be made between respondents and non-respondents on these characteristics.

Simple items were use to assess ethnicity, "What is your ethnic group?" ("White; Mixed; Asian or Asian British; Black or Black British; Chinese; Other; do not wish to answer") and marital status, "What is your marital status?" ("Single; Married; Cohabiting/living with partner; Divorced/separated; Widowed"). For analyses the ethnicity question was recoded into white or non-white because there were so few participants who were non-white.

Individual socioeconomic deprivation was assessed by a score made up of three demographic items, as in Studies 1 and 2. "Does your household have a car or van?" ("no; yes, 1; more than 1"); "Please tick the box which best describes your living arrangement: rent from local authority; rent from private landlord; own home; other"; and "What is your highest level of educational or professional qualification you have obtained?" ("GCSE/O-level/CSE; Vocational qualifications (e.g. NVQ 1+2); A-level or equivalent (e.g. NVQ3); Bachelor Degree or equivalent (e.g. NVQ4); Other; No formal qualifications; Still studying"). One 'deprivation' point was given for each of the following; the household not owning a car; not owning the home and having no educational qualifications. This resulted in the individual deprivation score ranging from 0-3 with 0 representing the most affluent group and 3 the most deprived.

As in the first three studies of this thesis, analysing the UK FS Trial data, postcode data were used to link participants' area of residence to information from census enumeration districts (based on an average of around 460 residents) to index neighbourhood-level deprivation (Townsend Material Deprivation Index; Townsend et al., 1988) using data from the 1991 census (Crown Copyright, 1991). A Townsend score of zero represents the national average, negative values represent below-average deprivation. The Townsend

Index allowed comparisons to be made between respondents and non-respondents and also provided an external validity check for the individual deprivation score.

*Health behaviours.* Smoking was assessed with the item, "Please tick the box that best describes your smoking habits: Never-smoker/non-smoker; Ex-smoker; Smoker". Two questions asked about fruit and vegetable consumption based on the DINE method for diet assessment (Roe, Strong, Whiteside, Neil, & Mant, 1994), "On a typical day how many servings of the following would you eat?" The fruit item read, "Fruit (fresh, frozen or canned)? For example, one apple counts as one serving". The vegetable item read, "Vegetables (including salad, but excluding potatoes)? For example a handful of carrots counts as one serving". Alcohol intake was measured with the question, "In a typical week how many units of alcohol would you consume? For example a unit is a small glass of wine or half a pint of lager". In all three cases an empty box was provided with the instruction, "Please enter the number of servings/units in the box".

Physical activity was assessed with two questions, one about vigorous activity and the other about moderate activity, "During the past 7 days, on how many days did you: Engage in vigorous activity that caused you to breathe much harder than normal and sweat (e.g. swimming, jogging, aerobics, football)?" and "Engage in moderate activity that caused you to breathe somewhat harder than normal (e.g. cycling, gardening, dancing, brisk walking)?" For each question participants were asked to write how many days per week they had engaged in that activity, and for how many minutes per day. "Don't know/not sure" was also a response option. The questions were based on the International Physical Activity Questionnaire (Booth, 2000) and the Baecke Questionnaire of Habitual Physical Activity (Baecke, Burema, & Frijters, 1982). For the purposes of analyses participants were categorised as either meeting physical activity recommendations (e.g. 3 days of at least 20 minutes of vigorous activity, or 5 days of at least 30 minutes of moderate activity; Department of Health, 2004) or not meeting the recommendations.

*Health related factors.* Body Mass Index (BMI) was calculated based on simple measures of height and weight. The height question asked, "How tall are you?" There was the option of either providing the answer in feet and inches or in centimetres. The weight question asked, "How much do you weigh?" Again, there was the option of providing the

answer in either stones and pounds or kilograms. BMI was calculated as weight in kgs/height in metres$^2$.

Family history of bowel cancer in FDR was assessed with the question, "Have any members of your family (blood relatives, not relatives by marriage) had bowel cancer?" "Options were mother; father, son(s); daughter(s); sister(s); brother(s) with participants asked to indicate "yes; no; don't know; not applicable" for each relative. These responses were categorised as none, one, and two or more for initial analyses but then coded into none and one or more for further analyses. Self-report measures of a family history of cancer in FDR were found to be accurate and valuable in a recent study (Murff, Spigel, & Syngal, 2004).

Bowel symptoms over the past three months were assessed with a list of 7 symptoms (constipation, haemorrhoids, diarrhoea, wind, pains in abdomen, incontinence, blood in stools), as used in the UK FS Trial (Robb, Miles, & Wardle, 2004). Symptom frequency was rated as "no; occasionally; frequently". A total symptoms score was calculated by totaling the number of symptoms that were experienced occasionally or frequently. The total symptoms score was divided into 3 groups for analyses: zero or one symptom; two or three symptoms; and four or more symptoms. Subjective health was assessed with the item, "Would you say that for someone of your age your own health in general is: excellent; good; fair; poor" (Health Survey for England, 1996).

Diagnosed bowel conditions were assessed with a list of 5 conditions (irritable bowel, diverticular disease, ulcerative colitis, Crohn's disease, abdominal hernia), as used in the UK FS Trial (Wardle et al., 2000). The response options were "yes; no".

*Knowledge of bowel cancer.* Knowledge of bowel cancer was assessed with 10 statements, for each of which participants were requested to tick one of five response options ("strongly disagree, disagree, not sure, agree, strongly agree"). The statements were based on the information given in the leaflet. The statements were, "There are things I can do to control whether I get bowel cancer or not; People can still be at risk of bowel cancer even if no one in the family has it; Regular exercise can reduce the risk of bowel cancer; Men are at slightly higher risk of getting bowel cancer than women; Smoking increases the risk of

developing bowel cancer; People can still be at risk of bowel cancer even if they have no symptoms; Being overweight or obese increases the risk of bowel cancer; A diet high in red and processed meat increases the risk of bowel cancer; Bowel cancer can develop from polyps in the bowel; Older people are more at risk of bowel cancer". A total knowledge score was calculated by allocating one point for each item participants "agreed" or "strongly agreed" with. Scores ranged from 0-10.

*Dispositional optimism.* Dispositional optimism was assessed with the revised version of the Life Orientation Test (LOT-R: Scheier, Carver, & Bridges, 1994). The LOT-R contains 6 items, 3 positively phrased ("In uncertain times, I usually expect the best"; "I'm always optimistic about my future"; "Overall, I expect more good things to happened to me than bad"), and 3 negatively phrased ("If something can go wrong for me, it will"; "I hardly ever expect things to go my way"; "I rarely count on good things happening to me"). The response options were "strongly disagree, disagree, not sure, agree, strongly agree". Negatively worded items were reverse scored and totalled with the positively worded items to yield an overall dispositional optimism score, with higher scores reflecting greater optimism. Scores ranged from 0-24. Internal reliability was high with a Cronbach's $\alpha$=0.81.

*Emotional impact.* The emotional impact of the intervention was assessed with items on bowel cancer worry and state anxiety to see if they were raised in the intervention groups. Worry was measured with the question, "How worried are you about getting bowel cancer?" ("Not worried at all; A bit worried; Quite worried; Very worried"), as used in the UK FS Trial (Wardle et al., 2000). I was interested in assessing any detrimental effects of the intervention so I was most interested in people who were either "quite worried" or "very worried". Therefore for analyses, responses were coded into two groups; not at all worried/a bit worried and quite/very worried. State anxiety was recorded with the shortened, 6-item version of the Spielberger State Trait Anxiety Inventory (STAI; Spielberger, 1983; Marteau & Bekker, 1992). Respondents were asked to indicate on a four-point Likert type scale ranging from "not at all" to "very much" how they feel right now; calm, tense, upset, relaxed, content, worried. Internal reliability of the STAI was high with a Cronbach's $\alpha$=0.84.

*Interest in screening.* Interest in bowel screening was assessed with the item, "If you were invited to have a bowel screening test, would you take up the offer?" ("Yes definitely; Yes, probably; Probably not; Definitely not") as used by Wardle et al. (2000).

*Beliefs in the importance of screening.* Participants' beliefs about the importance of the introduction of bowel screening were assessed with the question, "How important do you think it is that this country introduces a nationwide bowel screening programme?" ("Very important; Important; Not sure; Unimportant; Very unimportant").

*Help seeking behaviour.* Participants' willingness to seek help about bowel problems was measured with two questions used by McCaffery et al. (2003). The first asked, "If you noticed a change in your bowel habits which lasted for more than two weeks would you...." ("Go to your GP to have it checked out; Wait to see if it cleared up; Ignore it and hope it went away by itself; Seek advice from a family member or friend?"). The second question asked, "If you noticed blood in your bowel motions (stool) for more than two weeks would you.....". ("Go to your GP to have it checked out; Wait to see if it cleared up; Ignore it and hope it went away by itself; Seek advice from a family member or a friend?").

### *9.2.8. Analysis of results*

Results were analysed using SPSS (Version 10.1). One-sample t-tests were used to detect significant deviations from 0 for Townsend scores (0 represents the national average for England and Wales), and also to detect an optimistic bias in perceived risk with a significant deviation from the midpoint 0 (the score representing average risk). Independent-samples t-tests were employed to explore differences in age and Townsend scores for respondents and non-respondents. A Chi square test was used to examine differences in gender between respondents and non-respondents.

Spearman's rhos were used to explore the degree of association between ordinal and interval variables; the individual deprivation score and Townsend scores; comparative and absolute perceived risk and comparative perceived risk and dispositional optimism. A Pearson correlation assessed the degree of association between absolute perceived risk and dispositional optimism.

Chi square tests and ANOVAs were used to check the randomisation procedure. These determined if there were any significant differences between the three groups in terms of demographic characteristics and health-related factors.

The study employed the intention to treat principle and so all participants were included in the analyses whether they indicated that they had read the leaflet or not. This approach was taken to assess the likely impact of the intervention as a public health tool. However, I have also reported in some instances the results only for people who had indicated they read the leaflet because from an individual perspective it is interesting to know whether the leaflet worked. Chi square tests and ANOVAs were used to examine the impact of the intervention across the three groups. The outcome measures were; perceived risk, emotional impact, knowledge about bowel cancer, interest in screening, the importance of screening, and help seeking. Chi square tests were used for categorical data and ANOVAS were used on interval data. A loglinear analysis was performed to determine whether the relationship between perceived risk and screening interest differed by group.

Logistic regressions were used to examine the associations between perceived risk, group, age, gender, family history and bowel symptoms. Because of the pattern of results comparative perceived risk measure was dichotomised: those perceiving their risk as lower than average versus those seeing it as the same or higher than average, and those perceiving their risk as lower and the same versus higher than average.

## 9.3. Results

### *9.3.1. Response rate*

Of the 3185 questionnaires sent out, 61% (n=1945) were returned and included in the analyses, see Table 9.1. Four participants completed the questionnaire but removed the ID number from the top right hand corner of the questionnaire which meant that I could not match their gender and date of birth to their responses so they were excluded. Two questionnaires were returned with no ID number on the questionnaire which was an

administration error when they were sent out, they were similarly excluded from the analyses. Another administration error was that two questionnaires were given the same ID number and so they were not included in the analyses. Seven completed questionnaires were excluded because they appeared to have been completed by the wrong person. For example, the participant was supposed to be male but they had completed a comparative risk question for breast cancer but not a risk question for prostate cancer. It is of course possible that they may have been the correct participant but had just completed the wrong comparative risk question, so as a double check I examined their self-reported weight and height, and for all seven, the anthropometric measures were not consistent with the gender of the target participant. Eleven questionnaires were returned blank and one reminder questionnaire was returned blank with a note from the participant explaining that they had completed the first questionnaire. I did not receive this first questionnaire. Thirty-four questionnaires were returned as the participant was no longer at the address. A wife of a participant phoned me to say that her husband had recently had a stroke and was not well enough to complete the questionnaire. A more accurate response rate for the sample may be 62% if one removes the participants who were no longer living at the address supplied by the GPs (n=34), reducing the denominator to n=3151.

Considering that this study was conducted during a period when the Royal Mail was in crisis (The Guardian, May 19, 2004), the response rate is surprisingly high. Reports at the time suggested that as few as 57% of letters were reaching their destination on time. The study relied on the participants receiving their questionnaire and the completed questionnaire reaching me. Therefore a response rate of around 61-62% is satisfactory and similar to the response rate of other GP practice based surveys (Walsh, 1994).

**Table 9.1: Response rate**

| | n (%) |
|---|---|
| Total number of questionnaires sent out | 3185 (100) |
| Completed questionnaires returned | 1945 (61) |
| Completed questionnaires returned with ID number missing | 6 (0.002) |
| Completed questionnaires returned with same ID number | 2 (0.0006) |
| Completed questionnaires which appear to have been completed by the wrong person | 7 (0.002) |
| Returned blank | 11 (0.003) |
| Returned reminder questionnaire blank but claimed to have completed first questionnaire which I did not receive | 1 (0.0003) |
| Returned as participant no longer at address | 34 (0.01) |
| Not completed due to ill health | 1 (0.0003) |
| Response rate 1945+6+2/3185-34=1953/3151=62% | |

### *9.3.2. Demographic characteristics and response rates*

As expected, with randomisation of groups this size, there were no differences in gender, age or Townsend Material Deprivation score score, see Table 9.2. There was also no significant difference between the groups in response rate, with each group having a response rate of around 61%. Townsend scores were available for 3,104 participants[28]. The sample as a whole was significantly more affluent than the national average for England and Wales where the mean is zero ($t(3103)=-26.39$, $p<0.001$).

[28] Townsend scores were not available for the whole sample because of inaccuracies in postcode details in the lists from the GPs and participants living in new houses for whom Townsend scores had not yet been calculated.

**Table 9.2: Demographic characteristics and response rate of the three groups**

| | Total | Group 1 Control | Group 2 Risk factor information | Group 3 Risk factor and screening | Significance of difference |
|---|---|---|---|---|---|
| All cases N (%) | 3185 | 1056 (33.2) | 1053 (33.1) | 1076 (33.8) | |
| Gender N (%)[29] | | | | | |
| Female | 1543 (48.4) | 514 (48.7) | 495 (47.0) | 534 (49.6) | |
| Male | 1641 (51.5) | 542 (51.3) | 557 (52.9) | 542 (50.4) | $\chi^2(4, 3185)=3.47$, $p=0.483$ |
| Age Mean (sd) | 54.8 (5.74) | 54.7 (5.78) | 54.6 (5.70) | 55.0 (5.76) | $F(2, 3184)=0.78$, $p=0.460$ |
| Townsend score Mean (sd) | -1.26 (2.65) | -1.24 (2.64) | -1.21 (2.75) | -1.31 (2.56) | $F(2, 3103)=0.37$, $p=0.688$ |
| Response rate N (%) | 1945 (61.1) | 648 (61.4) | 637 (60.5) | 660 (61.3) | $\chi^2(2, 3185)=0.22$, $p=0.897$ |

### *9.3.3. Respondents vs. non-respondents*

The lists obtained from the GP surgeries provided information on gender, age, and Townsend scores for each patients' postcode. This allowed comparisons to be made between respondents and non-respondents on these characteristics.

Women (52%) were slightly more likely to return the questionnaire than men (48%), see Table 9.3. Respondents were slightly older than non-respondents, and came from areas with considerably lower Townsend scores ($M$=-1.44 $SD$=2.58) than non-respondents ($M$=0.97 $SD$=2.73), indicating that they lived in less deprived neighbourhoods.

[29] One participant was not identified as being male or female on the lists obtained from the GP and it was not possible to determine the gender from the title or first name.

**Table 9.3: Comparing respondents with non-respondents**

| | Total | Respondents | Non-respondents | Significance |
|---|---|---|---|---|
| All cases N (%) | 3185 | 1945 (61.1) | 1240 (38.9) | |
| Gender N (%) | | | | |
| Female | 1543 (48.4) | 1015 (52.2) | 528 (42.6) | |
| Male | 1641 (51.5) | 930 (47.8) | 711 (57.3) | $\chi^2(2, 3185)=29.32, p<0.001$ |
| Age Mean (sd) | 54.8 (5.74) | 55.0 (5.77) | 54.4 (5.68) | $F(1, 3184)=8.40, p=0.004$ |
| Townsend score Mean (sd) | -1.25 (2.65) | -1.44 (2.58) | 0.97 (2.73) | $F(1, 3103)=22.96, p<0.001$ |

### *9.3.4. Demographic characteristics of respondents*

The three groups did not differ on any demographic characteristic, see Table 9.4, therefore the sample is described as a whole. As noted above, 52% of respondents were female. Participants were predominantly White (98%), married or cohabiting (78%), and had a mean age of 55 years. Only 2% of participants were categorised as being in the most deprived group of the individual deprivation measure, while 66% fell into the most affluent group.

**Table 9.4: Demographic characteristics of respondents in the three groups**

| | Total | Group 1 Control n=648 | Group 2 Risk factor information n=637 | Group 3 Risk factor and screening information n=660 | Significance of difference |
|---|---|---|---|---|---|
| Gender N (%) | | | | | |
| Female | 1015 (52.2) | 345 (53.2) | 314 (49.3) | 356 (53.9( | |
| Male | 930 (47.8) | 303 (46.8) | 323 (50.7) | 304 (446.1) | $\chi^2(2, 1945)=3.24$, p=0.198 |
| Age Mean (sd) | 55.0 (5.77) | 54.8 (5.75) | 54.8 (5.87) | 55.4 (5.69) | F(2, 1944)=2.54, p=0.079 |
| Ethnicity N (%) | | | | | |
| White | 1883 (98.4) | 630 (98.0) | 623 (98.9) | 630 (98.3) | |
| Non-white | 31 (1.6) | 13 (2.0) | 7 (1.1) | 11 (1.7) | $\chi^2(2, 1914)=1.71$, p=0.425 |
| Marital status N (%) | | | | | |
| Married | 1333 (69.5) | 440 (68.4) | 440 (69.7) | 453 (70.3) | |
| Cohabiting | 154 (8.0) | 51 (7.9) | 50 (7.9) | 53 (8.2) | |
| Divorced/separated | 239 (12.5) | 82 (12.8) | 78 (12.4) | 79 (12.3) | |
| Widowed | 61 (3.2) | 17 (2.6) | 22 (3.5) | 22 (3.4) | |
| Single | 131 (6.8) | 53 (8.2) | 41 (6.5) | 37 (5.7) | $\chi^2(8, 1918)=4.26$, p=0.833 |
| Townsend score Mean (sd) | -1.44 (2.58) | -1.44 (2.56) | -1.38 (2.73) | -1.49 (2.46) | F(2, 1886)=0.32, p=0.722 |
| Individual deprivation score | | | | | |
| 0 (affluent) | 1228 (66.5) | 434 (69.8) | 399 (65.6) | 395 (63.9) | |
| 1 | 450 (24.4 | 134 (21.5) | 151 (24.8) | 165 (26.7) | |
| 2 | 138 (7.5) | 41 (6.6) | 46 (7.6) | 51 (8.3) | |
| 3 (deprived) | 32(1.7 | 13 (2.1) | 12 (2.0) | 7 (1.1) | $\chi^2(6, 1848)=8.27$, p=0.219 |

### *9.3.5. Health related factors across the three groups*

The three groups did not differ significantly on any health related factor with the exception of subjective health, see Table 9.5. The factors that did not differ by group will be described for the total sample. Over half of the sample had never smoked (51%), 34% were ex-smokers and 15% of the sample were current smokers. Less than a third of participants were meeting physical activity recommendations (29%), and the mean BMI for the sample was 26 (*SD*=4.75), indicating that on average they were overweight. Alcohol consumption

was well within the recommended weekly intake (number of units $M$=8.3, $SD$=10.4), and consumption of fruits and vegetables almost amounted to the recommended total of five servings per day (fruit servings $M$=2.2, $SD$=1.34; vegetable servings $M$=2.6, $SD$=1.23).

8% of respondents reported having a family history of bowel cancer among FDRs, see Table 9.5 59% reported having had more than one bowel symptom in the past 3 months and 80% believed their health was good or excellent. However, the three groups differed significantly in subjective health with those in Group 3 slightly less likely to describe their health as excellent (15%) compared to those in Groups 1 (20%) and 2 (22%), see Table 9.5. This difference was controlled for in the logistic regression.

Few participants reported having bowel conditions, 13% had irritable bowel, 4% had diverticular disease, 1% had ulcerative colitis and 1% had Crohn's disease.

**Table 9.5: Health related factors and the three groups**

| | Total | Group 1 Control n=648 | Group 2 Risk factor information n=637 | Group 3 Risk factor and screening information n=660 | Significance of difference |
|---|---|---|---|---|---|
| Smoking % | | | | | |
| Never smoked | 51.1 | 50.0 | 51.8 | 51.6 | |
| Ex-smoker | 33.6 | 36.4 | 31.9 | 32.5 | |
| Smoker | 15.2 | 13.6 | 16.3 | 15.9 | $\chi^2(4, 1918)=4.38$, p=0.358 |
| Meeting physical activity recommendations (%) | | | | | |
| Yes | 29.3 | 27.9 | 31.2 | 28.8 | |
| No | 70.7 | 72.1 | 68.8 | 71.2 | $\chi^2(2, 1945)=1.83$, p=0.401 |
| BMI Mean (sd) | 26.2 (4.75) | 26.4 (4.76) | 26.4 (5.04) | 25.9 (4.43) | F(2, 1901)=1.88, p=0.154 |
| Units of alcohol per week Mean (sd) | 8.3 (10.4) | 8.3 (9.44) | 8.53 (10.82) | 8.17 (10.78) | F(2, 1896)=0.19, p=0.823 |
| Servings of fruit per day Mean (sd) | 2.2 (1.34) | 2.1 (1.36) | 2.3 (1.37) | 2.2 (1.28) | F(2, 1903)=1.89, p=0.153 |
| Servings of vegetables per day Mean (sd) | 2.6 (1.23) | 2.6 (1.34) | 2.54 (1.18) | 2.5 (1.18) | F(2, 1919)=1.72, p=0.179 |
| Family history of bowel cancer (FDR) % | | | | | |
| 0 | 91.6 | 91.8 | 91.8 | 91.2 | |
| 1 | 7.7 | 7.6 | 7.7 | 7.9 | |
| 2+ | 0.7 | 0.6 | 0.5 | 0.9 | $\chi^2(4, 1945)=1.03$, p=0.905 |
| Bowel symptoms % | | | | | |
| 0,1 | 41.3 | 41.0 | 43.2 | 39.8 | |
| 2-3 | 39.4 | 38.3 | 39.9 | 40.0 | |
| 4+ | 19.3 | 20.7 | 17.0 | 20.2 | $\chi^2(4, 1945)=3.90$, p=0.420 |
| Subjective health % | | | | | |
| Excellent | 19.2 | 20.3 | 22.1 | 15.5 | |
| Good | 60.7 | 61.6 | 59.5 | 60.9 | |
| Fair | 17.5 | 16.1 | 16.7 | 19.8 | |
| Poor | 2.5 | 2.0 | 1.7 | 3.8 | $\chi^2(6, 1933)=17.23$, p=0.008 |

Table 9.5 continued

| | Total | Group 1 Control n=618 | Group 2 Risk factor information n=637 | Group 3 Risk factor and screening information n=660 | Significance of difference |
|---|---|---|---|---|---|
| Bowel problems % | | | | | |
| Irritable bowel | 12.2 | 12.9 | 11.7 | 12.1 | $\chi^2(2, 1871)=0.44$, p=0.804 |
| Diverticular disease | 4.0 | 4.0 | 3.8 | 4.1 | $\chi^2(2, 1839)=0.09$, p=0.956 |
| Ulcerative colitis | 1.3 | 1.6 | 1.5 | 0.8 | $\chi^2(2, 1825)=1.89$, p=0.388 |
| Crohn's disease | 0.6 | 0.8 | 0.8 | 0.2 | $\chi^2(2, 1816)=3.03$, p=0.219 |

### *9.3.6. Manipulation check*

In the group given risk factor information only, 67% (n=424) indicated that they had read the leaflet, 3% (n=21) indicated that they had not read the leaflet, and 30% (n=192) missed out the question. In the group given risk factor and screening information, 72% (n=474) said they had read the leaflet, 4% (n=25) indicated that they had not read the leaflet, and 24% (n=161) missed out the question. A further manipulation check was increased knowledge of bowel cancer risk factors among the intervention groups compared with the control group. These results are described in the next section.

### *9.3.7. Knowledge about bowel cancer*

As predicted, levels of knowledge were particularly low in the control group, see Table 9.6. The control group were particularly unaware that men are at increased risk and that bowel cancer develops from polyps. However, 85% of the control group were aware that a person was still at risk even if they did not have a family history, and 63% agreed that a person could still be at risk even if they did not have any symptoms.

For every statement about bowel cancer, those in the intervention groups were significantly more knowledgeable, see Table 9.6. Respondents in the intervention groups were more aware than the control group that a diet high in red and processed meat, smoking, being

overweight or obese, being older, and being male increased the risk of developing bowel cancer. The intervention groups were also more aware that exercise can reduce risk, people can still be at risk even if no one in the family has it, people are still at risk even if they have no symptoms, and that bowel cancer develops from polyps, see Table 9.6.

Those in the intervention groups were also significantly more aware that there are things that they can do to control whether they get bowel cancer or not, see Table 9.6. This suggests that providing participants with information on risk factors increased their sense of self-efficacy.

When the analyses were repeated only looking at those people who indicated that they had read the leaflet the effects were even stronger. For each knowledge item, people who indicated that they had read the leaflet were significantly more knowledgeable than those in the intervention groups who had not read the leaflet. The mean knowledge score (calculated by totalling the number of knowledge items answered correctly) for those reading the leaflet was $M$=8.7 $SD$=2.1 compared with $M$=7.3 $SD$=2.8 for those not indicating they had read the leaflet ($t(1295)=8.76$, $p<0.001$).

**Table 9.6: Knowledge about bowel cancer**

| | Group1 Control (n=648) | Group 2 Risk factor information (n=637) | Group 3 Risk factor and screening information (n=660) | Significance of difference |
|---|---|---|---|---|
| % aware that each factor increased risk for bowel cancer | | | | |
| Inactivity | 42.2% | 78.4% | 77.7% | $\chi^2(8, 1930)= 265.1$, $p<0.001$ |
| Diet high in red meat | 45.0% | 86.8% | 83.0% | $\chi^2(8, 1932)=357.5$, $p<0.001$ |
| Smoking | 43.1% | 84.7% | 83.3% | $\chi^2(8, 1929)=373.4$, $p<0.001$ |
| Being overweight | 48.5% | 86.0% | 84.1% | $\chi^2(8, 1933)=318.9$. $p<0.001$ |
| Increasing age | 54.6% | 87.7% | 85.2% | $\chi^2(8, 1925)=320.0$, $p<0.001$ |
| Being male | 20.7% | 80.2% | 78.0% | $\chi^2(8, 1931)=624.0$, $p<0.001$ |
| Still at risk even if no family history | 85.4% | 94.2% | 92.7% | $\chi^2(8, 1931)=41.5$, $p<0.001$ |
| Still at risk even if no symptoms | 62.9% | 90.0% | 86.8% | $\chi^2(8, 1933)=210.0$, $p<0.001$ |
| Having polyps | 39.5% | 81.7 | 82.7 | $\chi^2(8, 1926)=382.0$, $p<0.001$ |
| % believe can control whether get bowel cancer | 56.9 | 73.3 | 71.2 | $\chi^2(8, 1928)=54.0$, $p<0.001$ |

### *9.3.8. Does dispositional optimism or education moderate the effect of the leaflet?*

*Knowledge and dispositional optimism.* There were no significant difference across the three groups in dispositional optimism ($F(2,1891)=0.58$, $p=0.562$). The overall mean for the three groups combined was $M=15.2$ $SD=4.1$ which is similar to the norms reported by Scheier, Carver and Bridges (1994) ($M=14.3$ $SD=4.3$ for college students, and $M=15.2$ $SD=4.0$ for patients awaiting coronary artery bypass surgery). As predicted, those higher in dispositional optimism showed greater knowledge, even amongst those in the control group, see Table 9.7, however there was not a significant interaction between dispositional optimism and group ($F(2,1891)=2.5$, $p=0.080$) suggesting that dispositional optimism was not moderating the effect of the leaflet. The correlation between knowledge and dispositional optimism was $r=0.15$, $p<0.001$ and remained significant after controlling for education $r=0.14$, $p<0.001$.

**Table 9.7: Knowledge scores (Mean (sd)) and dispositional optimism**

| | Total | Group 1 Control n=648 | Group 2 Risk factor information n=637 | Group 3 Risk factor and screening information n=660 |
|---|---|---|---|---|
| Dispositional optimism tertiles | | | | |
| Low | 6.6 (3.0) | 4.6 (2.5) | 7.8 (2.5) | 7.6 (2.8) |
| Medium | 7.4 (2.8) | 5.0 (2.5) | 8.8 (2.0) | 8.5 (2.2) |
| High | 7.7 (2.7) | 5.4 (2.5) | 8.8 (2.0) | 8.8 (1.9) |
| Significance (per group) | F(1,1891)=50.1, p<0.001 | F(1,633)=11.4, p=0.001 | F(1,628)=23.9, p<0.001 | F(1,628)=30.0, p<0.001 |

*Knowledge and educational qualifications.* There were no significant differences in educational qualifications across the three groups ($\chi^2(8, 1897)=6.4$, p=0.603). As predicted, those with higher educational qualifications had greater knowledge scores even among the control group, see Table 9.8. There was not a significant interaction between educational qualifications and group (F(8, 1896)=1.78, p=0.76) indicating that education was not moderating the effect of the leaflet.

**Table 9.8: Knowledge scores and educational qualifications**

| | Total | Group1 Control (n=648) | Group 2 Risk factor information (n=637) | Group 3 Risk factor and screening information (n=660) |
|---|---|---|---|---|
| Educational qualifications | | | | |
| No formal qualifications | 6.6 (3.1) | 4.3 (2.6) | 7.8 (2.6) | 7.4 (2.9) |
| GCSE/O-level/NVQ1+2 | 7.0 (2.9) | 4.6 (2.5) | 8.5 (2.1) | 8.0 (2.5) |
| A-level/NVQ3 | 7.7 (2.7) | 5.4 (2.5) | 8.8 (1.9) | 9.0 (1.8) |
| Bachelor degree | 7.8 (2.6) | 5.8 (2.4) | 8.6 (2.1) | 8.8 (2.1) |
| Other/still studying | 7.1 (3.1) | 4.7 (2.7) | 8.6 (2.3) | 8.4 (2.5) |
| | F(4, 1897=12.3, p<0.001 | F(4, 633)=8.7, p<0.001 | F(4, 630)=4.4, p=0.002 | F(4, 632)=9.3, p<0.001 |

*9.3.9. Comparative optimism*

All three groups showed comparative optimism, with the means[30] in each group deviating significantly below zero, see Table 9.9. There was no significant difference in mean scores for perceived risk across the three groups (F(1902)=1.14, p=0.320).

When the analyses were re-run including only those who indicated that they had read the leaflet, there was still no significant difference across the three groups and the two intervention groups still showed significant optimistic biases. This suggests that neither intervention had a significant impact on debiasing optimistic beliefs.

**Table 9.9: Testing for optimistic bias**

| | Mean (sd) for comparative perceived risk | t | df | Significance of deviation from zero |
|---|---|---|---|---|
| Group 1 Control | | | | |
| 5 point scale | -0.18 (0.67) | -6.92 | 633 | p<0.001 |
| 3 point scale | -0.15 (0.56) | -6.94 | 633 | p<0.001 |
| Group 2 Risk factor information | | | | |
| 5 point scale | -0.14 (0.71) | -4.88 | 621 | p<0.001 |
| 3 point scale | -0.12 (0.65) | -4.50 | 621 | p<0.001 |
| Group 3 Risk factor and screening information | | | | |
| 5 point scale | -0.19 (0.72) | -6.75 | 640 | p<0.001 |
| 3 point scale | -0.16 (0.62) | -6.69 | 640 | p<0.001 |

*9.3.10. Comparative and absolute perceived risk and missing data*

*Comparative perceived risk.* In the control group, 25% saw their chance of developing bowel cancer as lower than others of the same sex and age (henceforth called lower than

[30] All participants responded on a 5-point scale but for analyses this was recoded into a three point scale, both are presented in Table 9.9.

average), 66% thought their risk was about the same (henceforth called average), and 9% thought their risk was higher, see Table 9.10[31].

In the risk factor information group, 28% thought their chances of developing bowel cancer was lower than average, 56% thought it was about average, and 16% thought it was higher, see Table 9.10. In the risk and screening information group, 29% saw their risk as lower than average, 58% saw it as average, and 13% saw it as higher. Thus if anything, the intervention increased the number comparative optimists, but it also increased the number of comparative pessimists. The two intervention groups had greater numbers of respondents reporting that their chances of developing bowel cancer were higher than average, compared to those in the control group. The two intervention groups had similarly high numbers of comparative optimists, but the risk factor information group had more comparative pessimists compared to the risk factor and screening information group (16% vs. 13%, respectively).

*Absolute perceived risk.* There was no significant difference across the three groups using the absolute measure of perceived risk, see Table 9.10. For the sample as a whole, people rated their chances of getting bowel cancer as 34% (range 0-100%, the range was also 0-100% within each of the 3 groups). When the analyses were re-run including only those who indicated that they had read the leaflet, there were still no significant differences in absolute perceived risk across the three groups. In the two intervention groups those who read the leaflet gave significantly higher absolute perceived risk estimates (36%) compared to those who had not read the leaflet (32%; $F(1, 1197)=8.0$, $p=0.005$).

*Missing data.* Among the whole sample, 2.2% of participants did not complete the comparative risk question. 7.2% of participants failed to complete the absolute risk question.

[31] Again, the responses to the 5-point scale are presented for the three groups in Table 9.10.

**Table 9.10: Comparative risk judgements**

| | Total | Group 1 Control n=648 | Group 2 Risk factor information n=637 | Group 3 Risk factor and screening information n=660 | Significance of difference |
|---|---|---|---|---|---|
| Comparative perceived risk 3-point scale % | | | | | |
| Lower | 27.1 | 24.6 | 27.7 | 29.2 | |
| The same | 60.3 | 66.2 | 56.4 | 58.2 | |
| Higher | 12.5 | 9.1 | 15.9 | 12.6 | $\chi^2(4, 1897)=19.7$, $p=0.001$ |
| Missing | 2.2 | 1.9 | 2.2 | 2.4 | |
| Comparative perceived risk 5-point scale % | | | | | |
| Much lower | 3.3 | 3.9 | 2.4 | 3.6 | |
| Lower | 23.8 | 20.7 | 25.2 | 25.6 | |
| The same | 60.3 | 66.2 | 56.4 | 58.2 | |
| Higher | 11.8 | 8.2 | 15.6 | 11.7 | |
| Much higher | 0.7 | 0.9 | 0.3 | 0.9 | $\chi^2$ (8, 1897)=28.9, $p<0.001$ |
| Absolute perceived risk *M (SD)* | 34.1 (20.9) | 33.4 (20.9) | 34.7 (21.0) | 34.4 (20.8) | F(2, 1804)=0.59, p=0.553 |
| Missing % | 7.2 | 6.3 | 7.5 | 7.7 | |

*Relationship between comparative and absolute perceived risk.* The measures of comparative and absolute perceived bowel cancer risk were found to be significantly related overall and within each of the three groups, see Table 9.11.

**Table 9.11: Correlations between comparative and absolute perceived risk**

| | Total | Group 1 Control n=648 | Group 2 Risk factor information n=637 | Group 3 Risk factor and screening information n=660 |
|---|---|---|---|---|
| Spearman's rho between comparative[32] and absolute perceived risk | 0.46** | 0.50** | 0.45** | 0.44** |

**p<0.01

Table 9.12 presents the mean levels of the absolute score for the three levels of comparative perceived risk. Overall, and within each group there was a significant linear association

[32] 5-point scale

with those reporting their risk to be lower than average showing the smallest absolute perceived risk scores while those perceiving their risk to be higher than average showing the largest absolute scores.

**Table 9.12: Mean (sd) levels of absolute perceived risk by comparative perceived risk**

| | Total | Group 1 Control n=648 | Group 2 Risk factor information n=637 | Group 3 Risk factor and screening information n=660 |
|---|---|---|---|---|
| Comparative perceived risk 3-point scale % | | | | |
| Lower | 20.7 (17.5) | 17.5 (16.2) | 22.3 (17.8) | 21.9 (18.0) |
| The same | 37.0 (18.8) | 36.8 (18.8) | 36.6 (19.1) | 37.5 (18.5) |
| Higher | 49.4 (21.9) | 51.3 (21.2) | 49.6 (21.3) | 47.9 (23.2) |
| Significance (per group) | F(1,1787)=416.1, p<0.001 | F(1,601)=173.8, p<0.001 | F(1,582)=128.2, p<0.001 | F(1,603)=122.1, p<0.001 |

*9.3.11. Perceived risk and dispositional optimism*

Dispositional optimism showed a significant but weak relationship with comparative perceived risk (Spearman's rho=-0.18, p<0.01) and absolute perceived risk (r=-0.20, p<0.01). For both measures, greater dispositional optimism was associated with lower perceived risk.

*9.3.12. Testing for debiasing in the targeted subgroups*

One of the key aims of the intervention was to reduce optimistic bias in those with no family history and few bowel symptoms. It was noted in the Methods section that is not appropriate to assess the impact of the intervention on men and people in the older age group using the comparative risk measure because of the nature of the comparative risk question. However, it was felt these results may be of interest and given that comparative and absolute perceived risk are significantly correlated they have been presented. Table 9.13 describes the extent of the optimistic bias for these subgroups for the three groups. Overall, the intervention failed to debias optimistic beliefs in men, those with no family history, and few bowel symptoms. Optimistic bias was eliminated in the older age group

(56-66 years) for those given risk factor information, see Table 9.13, but not for those given risk factor and screening information.

When the analyses were restricted to those indicating they had read the leaflet the pattern of results was the same as described in Table 9.13, with one exception. Among men given risk factor information the optimistic bias was removed.

**Table 9.13: Testing for debiasing in targeted subgroups**

| | Mean (sd) for comparative perceived risk | t | df | Significance of deviation from zero |
|---|---|---|---|---|
| No family history | | | | |
| Group 1 Control | -0.20 (0.53) | -8.97 | 584 | p<0.001 |
| Group 2 Risk factor information | -0.14 (0.64) | -5.16 | 571 | p<0.001 |
| Group 3 Risk and screening information | -0.21 (0.60) | -8.42 | 586 | p<0.001 |
| Few symptoms (0-1) | | | | |
| Group 1 Control | -0.26 (0.53) | -7.78 | 260 | p<0.001 |
| Group 2 Risk factor information | -0.24 (0.64) | -6.15 | 267 | p<0.001 |
| Group 3 Risk and screening information | -0.30 (0.63) | -7.46 | 252 | p<0.001 |
| Male | | | | |
| Group 1 Control | -0.12 (0.54) | -3.89 | 297 | p <0.001 |
| Group 2 Risk factor information | -0.12 (0.67) | -3.34 | 317 | p=0.001 |
| Group 3 Risk and screening information | -0.19 (0.61) | -5.30 | 296 | p<0.001 |
| Older age (56-66 years)[33] | | | | |
| Group 1 Control | -0.17 (0.52) | -5.50 | 269 | p<0.001 |
| Group 2 Risk factor information | -0.06 (0.67) | -1.37 | 268 | p=0.173 |
| Group 3 Risk and screening information | -0.12 (0.64) | -3.15 | 295 | p=0.002 |

### *9.3.13. Testing for increases in perceived risk using the absolute scale*

Using the absolute measure of perceived risk, there were no significant differences across the three groups among the targeted subgroups, see Table 9.14. Those receiving the risk information or risk and screening information were no more likely than the control group to see their risk as increased.

[33] The same pattern of results emerged if the sample was restricted to those aged 60 and older.

When the analyses were re-run including only those who indicated that they had read the leaflet there were no significant differences across the three groups among the targeted subgroups. The pattern of results was the same as that described in Table 9.14.

**Table 9.14: Testing for increases in perceived risk using the absolute scale**

| | Mean (sd) | Significance of difference |
|---|---|---|
| Male | | |
| Group 1 Control | 32.4 (21.2) | |
| Group 2 Risk factor information | 32.8 (21.2) | |
| Group 3 Risk and screening information | 32.7 (20.4) | F(2, 867)=0.02, p=0.982 |
| Older age (56-66 years)[34] | | |
| Group 1 Control | 37.0 (19.9) | |
| Group 2 Risk factor information | 37.3 (21.8) | |
| Group 3 Risk and screening information | 34.8 (20.8) | F(2,779)=1.10, p=0.333 |
| No family history | | |
| Group 1 Control | 32.3 (20.5) | |
| Group 2 Risk factor information | 34.1 (20.9) | |
| Group 3 Risk and screening information | 33.1 (20.4) | F(2, 1654)=1.07, p=0.343 |
| Few symptoms (0-1) | | |
| Group 1 Control | 30.3 (21.1) | |
| Group 2 Risk factor information | 31.5 (19.6) | |
| Group 3 Risk and screening information | 30.0 (19.8) | F(2, 727)=0.416, p=0.660 |

### *9.3.14. Summary of the impact of the intervention on the targeted subgroups*

Table 9.15 provides a summary of the impact of the intervention on the targeted subgroups, using Chi square and logistic regression analyses. Comparative optimism was not reduced in any of the targeted groups, indeed it was significantly increased among men in both intervention groups, and among those with no family history and few symptoms in the group receiving risk factor and screening information. However, comparative pessimism was significantly increased in all four targeted subgroups (men, older, no family history, few symptoms) receiving risk factor information, and significantly increased in older people and those with few symptoms who received risk factor and screening information. The details of these analyses are presented in the following two sections (9.3.15) and 9.3.16).

[34] The result was still non significant if the older age group was restricted to those aged 60 and older F(2,416)=1.185, p=0.307

**Table 9.15: Summary table of the impact of the intervention on the targeted subgroups**

| | Chi square Reduced number of comparative optimists? | | Univariate logistic regression Decreased comparative optimism (lower vs. the same or higher) | | Univariate logistic regression Increased comparative pessimism (lower or the same vs. higher) | |
|---|---|---|---|---|---|---|
| | Group 2 Risk information | Group 3 Risk and screening information | Group 2 Risk information | Group 3 Risk and screening information | Group 2 Risk information | Group 3 Risk and screening information |
| Are men preferentially sensitive to the intervention? | No | No | No* | No* | Yes | No |
| Are older people preferentially sensitive to the intervention? | No | No | No | No | Yes | Yes |
| Are people with no family history preferentially sensitive to the intervention? | No | No | No | No* | Yes | Borderline (p=0.058) |
| Are people with few symptoms preferentially sensitive to the intervention? | No | No | No | No* | Yes | Yes |

Yes=$p<0.05$; No=$p>0.05$; *=significantly *increased* optimism

*9.3.15. Analyses of gender, age, family history and symptomatic status*

Examining the means for comparative perceived risk may obscure the nature of the relationship between risk information and perceived risk. I therefore carried out a series of Chi square tests to determine the impact of the intervention on the proportions of people seeing their risk as lower than average, average or higher than average. The analyses were univariate, and were done individually per group e.g. for Group 1 the relationship between gender and perceived comparative risk is reported . Thus, it was not possible to compare the differences between groups statistically; this will be done in the logistic regression. However, these descriptive analyses have been included as they are useful in understanding the impact of the intervention on perceptions of risk for bowel cancer among the targeted subgroups.

In addition, I have included analyses on the subgroups not specifically targeted (e.g. women, the younger age group, those with a family history, those with symptoms) as it is also interesting to see the impact of the intervention on these groups and to compare with the results of Study 1. These additional subgroups were also included in the logistic regression analyses.

*Gender.* In the control group, 28% of women saw their risk as lower than average compared with 21% of men, although this difference was not statistically significant, see Table 9.16 column 1. Within the intervention groups, perceptions of risk did not differ significantly by gender. Providing risk factor information did not have the desired effect of reducing optimistic beliefs among males. Indeed, men in the intervention groups were more comparatively optimistic (30%) compared to men in the control group (21%), however in this analyses the difference was not tested statistically, see Table 9.16.

*Age.* In the control group, 26% of those aged 45-55 years reported their risk as lower than average compared to 24% of those aged 56-66 years, see Table 9.16. The greater difference between the two age groups was for perceiving oneself as at higher risk, with 11% of respondents in the younger group (45-55 years) rating their chances as higher

compared with 6% in the older age group (56-66 years), however the result was non-significant.

In the group given risk factor information only, respondents in the younger age group were more comparatively optimistic (30% vs. 25%) and comparatively pessimistic (13% vs. 20%) compared to the older age group suggesting that the intervention may have worked to reduce optimistic bias in the older age group although this result was of borderline significance (p=0.067) and so may have occurred by chance, see Table 9.16. The group given risk factor and screening information did not show a significant relationship between perceived risk of bowel cancer and age.

Comparing across the three groups, the biggest difference was in the number of participants having comparatively pessimistic beliefs among the older age group (56-66 years) in the intervention groups (control=6%; risk factor information=20%; risk factor and screening information=16%). This relationship will be further explored in the logistic regression.

*Family history.* As expected, in the control group 10% of those with a FDR with bowel cancer perceived their risk to be lower than average compared to 26% of those with no FDR(s). Those with a FDR were almost seven times more likely to judge their risk as higher compared with those with no family history (41% vs. 6%), see Table 9.16.

A similar pattern of results emerged in the two intervention groups. Among those given risk factor information only, 20% of those with a FDR with bowel cancer rated their risk as lower compared with 28% of those with no family history. Those with a family history were more than twice as likely to perceive their risk as higher compared with those with no FDRs (31% vs. 14% respectively), see Table 9.16. In the group given risk factor and screening information, 31% of respondents with no FDR perceived their chances of developing bowel cancer as lower than average compared with 12% of those with a positive family history in a FDR. Those with a family history were four times more likely to report their risk as higher than their peers compared with those with no FDRs (10% vs. 40%, respectively).

Comparing across the three groups, there was little evidence that the intervention had the intended effect of reducing the number of respondents with no family history feeling comparatively optimistic. In fact the opposite may be true as the intervention groups had more respondents with no family history perceiving their risk as lower than their peers (control=26%; risk factor information=28%; risk factor and screening information=31%), see Table 9.16.

*Symptomatic status.* In the control group, 30% of those with zero or one bowel symptom perceived their risk as lower than average compared with 18% of those with four or more bowel symptoms. Those with four or more bowel symptoms were more than three times more likely to report their risk as higher than average compared with those with zero or one bowel symptom (18% vs. 5%), see Table 9.16.

The intervention groups showed a similar pattern of results. 36% of respondents given risk factor information who had zero or one bowel symptom reported their risk as being lower than average compared with 14% who had four or more symptoms. Among those with zero or one symptom 12% reported their risk to be higher compared with 23% with four or more symptoms. In the group given risk factor and screening information, 39% of those with zero or one symptom saw their risk as lower than their peers compared with 16% of those with four or more symptoms. 10% of respondents with zero or one symptom rated their risk as higher compared with 22% of those with three or more symptoms.

Comparing across the three groups there is little to suggest that the intervention reduced comparatively optimistic beliefs among those with few symptoms. Indeed, as with family history the opposite may be true and the intervention may have exacerbated the bias, see Table 9.16.

**Table 9.16: Description of the proportions of perceived comparative risk across the three groups**

| | Group 1 control | | | | Group 2 risk factor information | | | | Group 3 risk and screening information | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Perceived risk | | | Significance | Perceived risk | | | Significance | Perceived risk | | | Significance |
| | Lower | The same | Higher | | Lower | The same | Higher | | Lower | The same | Higher | |
| Gender | | | | | | | | | | | | |
| Female | 28.1 | 62.7 | 9.2 | | 25.6 | 59.7 | 14.8 | | 28.6 | 57.5 | 13.9 | |
| Male | 21.1 | 69.8 | 9.1 | p=0.117 | 29.7 | 53.3 | 17.0 | p=0.278 | 29.8 | 59.0 | 11.2 | p=0.592 |
| Age | | | | | | | | | | | | |
| 45-55yrs | 25.7 | 63.1 | 11.2 | | 29.5 | 57.5 | 13.0 | | 30.6 | 59.2 | 10.2 | |
| 56-66yrs | 23.7 | 70.0 | 6.3 | p=0.516 | 25.3 | 55.0 | 19.7 | p=0.067 | 27.4 | 57.1 | 15.5 | p=0.119 |
| Family history | | | | | | | | | | | | |
| 0 | 26.2 | 67.5 | 6.3 | | 28.4 | 57.1 | 14.5 | | 30.8 | 59.2 | 9.9 | |
| 1+ | 9.8 | 49.0 | 41.2 | p<0.001 | 19.6 | 49.0 | 31.4 | p=0.006 | 12.3 | 47.4 | 40.4 | p<0.001 |
| Bowel symptoms | | | | | | | | | | | | |
| 0, 1 | 30.3 | 65.1 | 4.6 | | 35.8 | 52.6 | 11.6 | | 39.0 | 51.4 | 9.6 | |
| 2-3 | 22.5 | 68.4 | 9.0 | | 24.5 | 57.8 | 17.7 | | 26.0 | 62.8 | 11.1 | |
| 4+ | 18.3 | 63.4 | 18.3 | p<0.001 | 14.2 | 63.2 | 22.6 | p<0.001 | 16.3 | 62.0 | 21.7 | p<0.001 |

*9.3.16. Logistic regression of gender, age, family history and symptomatic status*

Because of the unpredicted pattern of results, that is that the intervention groups became both more comparatively optimistic and pessimistic (described in Table 9.10), logistic regressions were carried out i) to compare the proportion seeing their risk as lower vs. the same or higher, and ii) the proportion seeing risk as lower or the same vs. higher. All analyses controlled for subjective health as there was a significant difference across groups in this measure.

*Group.* Respondents given risk factor and screening information (Group 3) were significantly more optimistic than the control group, see Table 9.17, column 2. Those given risk factor information (Group 2) had greater odds of being comparatively pessimistic relative to the control group. Given the association between dispositional optimism and knowledge, the logistic regressions were repeated to explore whether dispositional optimism contributed to this unexpected pattern of results. Controlling for dispositional optimism made no impact on the pattern of results for the analyses comparing lower vs. the same and higher, however in the analyses comparing lower and the same vs. higher, those receiving risk factor and screening information were comparatively pessimistic relative to the control group (1.47 [1.01, 2.12]).

*Gender.* Among females there was no significant difference across groups when comparing lower vs. the same and higher. However, women given risk factor information had significantly greater odds of seeing their risk as higher than average compared with the control group.

Among males, those in the intervention groups were significantly more likely to see their risk as being lower than average, see Table 9.17 column 2. Men given risk factor information were also significantly more comparatively pessimistic compared to the control group, see Table 9.17 column 4. Those given risk factor and screening information were no more pessimistic than the control group.

*Age.* In the younger age group (45-55 years), those given risk factor and screening information were significantly more optimistic than those in the control group. There was no significant difference across groups in the younger age group in terms of pessimistic beliefs.

Among the older age group, there was no significant difference across groups in optimistic beliefs. However, those in the intervention groups had significantly greater odds of seeing their risk as higher relative to the control group, see Table 9.17 column 4.

*Family history.* In people without a family history of bowel cancer, respondents given risk factor and screening information were significantly more optimistic compared to the control group. Those with no family history given risk information were also significantly more pessimistic. Those without a family history who were in the risk factor and screening information group were also slightly more pessimistic although this result was of borderline significance.

Among people with a family history of bowel cancer, there were no differences across groups in perceived risk for either the analyses looking at more optimistic or more pessimistic beliefs, see Table 9.17 columns 2 and 4.

*Symptomatic status.* Among those with few symptoms (0, 1), those given risk factor and screening information were significantly more optimistic. Both intervention groups with few symptoms had more pessimistic beliefs, see Table 9.17 column 4.

Among respondents with two or more symptoms the only significant difference across groups was that those given risk factor information felt more pessimistic compared to those in the control group, see Table 9.17 column 4.

**Table 9.17: Logistic regression of gender, age, family history and symptomatic status on comparative perceived risk**

| | Univariate odds Increased optimism (lower vs. the same or higher) | Significance | Univariate odds Increased pessimism (lower or the same vs. higher) | Significance |
|---|---|---|---|---|
| Group | | | | |
| Group 1 Control | 1.00 | | 1.00 | |
| Group 2 Risk factor information | 0.87 [0.67, 1.12] | p=0.276 | 1.91 [1.35, 2.70] | p<0.001 |
| Group 3 Risk factor & screening information | 0.72 [0.55, 0.93] | p=0.011 | 1.34 [0.93, 1.91] | p=0.115 |
| Gender | | | | |
| **Female** | | | | |
| Group 1 Control | 1.00 | | 1.00 | |
| Group 2 Risk factor information | 1.13 [0.79, 1.61] | p=0.510 | 1.70 [1.05, 2.78] | p=0.032 |
| Group 3 Risk factor & screening information | 0.90 [0.64, 1.26] | p=0.532 | 1.51 [0.93, 2.44] | p=0.094 |
| **Male** | | | | |
| Group 1 Control | 1.00 | | 1.00 | |
| Group 2 Risk factor information | 0.64 [0.44, 0.94] | p=0.023 | 2.14 [1.30, 3.53] | p=0.003 |
| Group 3 Risk factor & screening information | 0.54 [0.37, 0.80] | p=0.002 | 1.14 [0.66, 1.96] | p=0.646 |
| Gender*Group | Wald=5.11 | p=0.078 | Wald=2.12 | p=0.347 |
| Male*Group 2 | 0.57 [0.34, 0.96] | p=0.035 | 1.17 [0.75, 1.80] | p=0.490 |
| Male*Group 3 | 0.62 [0.37, 1.04] | p=0.071 | 0.73 [0.45, 1.18] | p=0.200 |
| Age | | | | |
| **45-55 years** | | | | |
| Group 1 Control | 1.00 | | 1.00 | |
| Group 2 Risk factor information | 0.78 [0.55, 1.09] | p=0.150 | 1.16 [0.74, 1.82] | p=0.522 |
| Group 3 Risk factor & screening information | 0.64 [0.45, 0.90] | p=0.011 | 0.79 [0.49, 1.28] | p=0.345 |
| **56-66 years** | | | | |
| Group 1 Control | 1.00 | | 1.00 | |
| Group 2 Risk factor information | 0.99 [0.66, 1.48) | p=0.956 | 3.84 [2.15, 6.85] | p<0.001 |
| Group 3 Risk factor & screening information | 0.82 [0.55, 1.21] | p=0.316 | 2.68 [1.49, 4.82] | p=0.001 |

Table 9.17 continued

| | Univariate odds Increased optimism (lower vs. the same or higher) | Significance | Univariate odds Increased pessimism (lower or the same vs. higher) | Significance |
|---|---|---|---|---|
| Age*Group | Wald=1.23 | p=0.600 | Wald=8.05 | p=0.018 |
| 56-66 years*Group 2 | 1.27 [0.75, 2.16] | p=0.368 | 1.59 [1.03, 2.45] | p=0.038 |
| 56-66 years*Group3 | 1.26 [0.75, 2.11] | p=0.389 | 1.60 [0.99, 2.56] | p=0.053 |
| Family history | | | | |
| **No family history** | | | | |
| Group 1 Control | 1.00 | | 1.00 | |
| Group 2 Risk factor information | 0.89 [0.68, 1.16] | p=0.383 | 2.57 [1.70, 3.87] | p<0.001 |
| Group 3 Risk factor & screening information | 0.73 [0.56, 0.95] | p=0.018 | 1.52 [0.98, 2.35] | p=0.058 |
| **Positive family history** | | | | |
| Group 1 Control | 1.00 | | 1.00 | |
| Group 2 Risk factor information | 0.53 [0.155, 1.79] | p=0.304 | 0.67 [0.30, 1.52] | p=0.339 |
| Group 3 Risk factor & screening information | 0.44 [0.12, 1.63] | p=0.219 | 0.97 [0.44, 2.15] | p=0.942 |
| Family history*Group | Wald=0.787 | p=0.675 | Wald=42.10 | p<0.001 |
| Positive family history* Group 2 | 0.58 [0.17, 1.96] | p=0.378 | 3.02 [1.58, 5.78] | p=0.001 |
| Positive family history* Group 3 | 0.75 [0.21, 2.66] | p=0.659 | 5.55 [3.03, 10.16] | p<0.001 |
| Symptoms | | | | |
| **Low symptoms (0-1)** | | | | |
| Group 1 Control | 1.00 | | 1.00 | |
| Group 2 Risk factor information | 0.78 [0.54, 1.14] | p=0.203 | 2.74 [1.37, 5.47] | p=0.004 |
| Group 3 Risk factor & screening information | 0.63 [0.44, 0.92] | p=0.018 | 1.56 [0.93, 2.61] | p=0.038 |
| **High symptoms (2+)** | | | | |
| Group 1 Control | 1.00 | | 1.00 | |
| Group 2 Risk factor information | 0.96 [0.69, 1.38] | p=0.831 | 1.70 [1.13, 2.57] | p=0.011 |
| Group 3 Risk factor & screening information | 0.79 [0.56, 1.13] | p=0.201 | 1.12 [0.73, 1.70] | p=0.613 |
| Symptoms*Group | Wald=6.72 | p=0.035 | Wald=17.76 | p<0.001 |
| Symptom 3+*Group 2 | 1.45 [1.08, 1.93] | p=0.013 | 2.04 [1.46, 2.84] | p<0.001 |
| Symptom 3+*Group 3 | 1.19 [0.90, 1.57] | p=0.217 | 1.34 [0.95, 1.91] | p=0.098 |

All analyses controlled for subjective health

*Logistic regression analyses only among those who indicated they had read the leaflet.* When the analyses were restricted to those indicating that they had read the leaflet exactly the same pattern of results emerged for increased optimism (lower vs. the same or higher) for both intervention groups in men, the older age group, those with no family history, and few symptoms. In terms of increased pessimism (lower or the same vs. higher), the pattern of results was the same for those receiving risk factor information. Among those receiving risk factor and screening information the same pattern or results emerged for men, those in the older age group, and low symptoms, but those with no family history had significantly greater odds of increased pessimism. Thus restricting the analyses to include only those who had read the leaflet did not impact greatly on the results.

### *9.3.17. Emotional impact*

There was no significant difference in state anxiety across the three groups, see Table 9.18. The mean level of state anxiety for the sample was $M$=10.7 $SD$=3.76 which is similar to the finding in Study 1 $M$=10.6 $SD$=3.87, and represents a lower level of anxiety than previous studies have found (Marteau & Bekker, 1992).

The worry scale was dichotomized into those who were not at all worried or a bit worried and those who were quite or very worried, because I was most interested in detecting whether the intervention had a detrimental impact. The latter group was conceived as measuring a 'harmful' amount of worry whereas being not at all or a bit worried was conceived as having little detrimental effect on psychological wellbeing. Worry did not differ significantly across the three groups, see Table 9.18. 90% of the total sample described themselves as being not at all or a bit worried. There was a slight non-significant trend for the intervention groups to be quite or very worried compared to the control group (11% vs. 9%). Taken together, the anxiety and worry results suggest that providing simple risk factor information had no adverse effect on psychological wellbeing.

**Table 9.18: Emotional impact of the intervention**

| | Total | Group 1 Control n=648 | Group 2 Risk factor information n=637 | Group 3 Risk factor and screening information n=660 | Significance of difference |
|---|---|---|---|---|---|
| Anxiety Mean (sd) | 10.7 (3.76) | 10.6 (3.79) | 10.6 (3.66) | 10.8 (3.83) | F(2, 1931)=0.47, p=0.626 |
| Bowel cancer worry % | | | | | |
| Not at all/ a bit worried (n=1716) | 89.8 | 91.2 | 89.3 | 89.0 | |
| Quite/very worried (n=194) | 10.2 | 8.8 | 10.7 | 11.0 | $\chi^2(2, 1910)=2.04$, p=0.360 |

*9.3.18. Interest in screening, help seeking and beliefs about the importance of screening*

Interest in bowel screening did not differ significantly across the three groups. Overall, interest was extremely high with 93% of participants reporting that they would definitely (63%) or probably (29%) take up an invitation to have a bowel screening test, see Table 9.19. 6% reported that they probably would not take up the offer, and 1% reported that they definitely would not take up the offer.

There was no difference across the three groups in seeking medical help for bowel symptoms. 93% of respondents correctly said that they would visit their GP if they noticed blood in their stools for more than two weeks, see Table 9.19. 6% reported that they would wait to see if it cleared up, and less than 1% said they would ignore it and hope that it went away, or would seek advice from family or a friend.

Compared to noticing blood in their stool, respondents (67%) were less likely to visit their GP if they noticed a change in bowel habit for more than two weeks, see Table 9.19. 29% reported that they would wait to see if it cleared up, 2% would ignore it and hope it went away, and 1% would seek advice from family or a friend.

Respondents who were given information on bowel screening were more likely (65%) to report that it was very important that the country introduces bowel screening compared to

those only given risk factor information (59%) and the control group (56%), see Table 9.19. Those in the control group were most likely to state that they were not sure how important it was that the country introduced bowel screening (11%) compared to those given risk factor information (7%) and those given risk factor and screening information (8%).

**Table 9.19: Importance of screening, screening interest and help seeking behaviour**

| | Total | Group 1 Control n=648 | Group 2 Risk factor information n=637 | Group 3 Risk factor and screening information n=660 | Significance of difference |
|---|---|---|---|---|---|
| Interest in bowel screening % | | | | | |
| Yes definitely | 63.3 | 63.0 | 62.8 | 64.0 | |
| Yes probably | 29.4 | 30.5 | 29.3 | 28.5 | |
| Probably not | 6.2 | 5.4 | 7.3 | 6.0 | |
| Definitely not | 1.0 | 1.1 | 0.6 | 1.4 | $\chi^2(6, 1923)=4.19$, $p<0.652$ |
| If notice blood in stool for more than 2 weeks % | | | | | |
| Visit GP | 93.2 | 93.9 | 92.4 | 93.3 | |
| Wait to see if it cleared up | 6.1 | 5.6 | 6.6 | 5.9 | |
| Ignore it and hope it went away | 0.6 | 0.2 | 0.8 | 0.8 | |
| Seek advice from family/friend | 0.2 | 0.3 | 0.2 | 0 | $\chi^2(6, 1916)=5.58$, $p=0.472$ |
| If notice change in bowel habit for more than 2 weeks % | | | | | |
| Visit GP | 66.9 | 66.2 | 68.5 | 66.1 | |
| Wait to see if it cleared up | 29.4 | 29.4 | 28.2 | 30.6 | |
| Ignore it and hope it went away | 2.5 | 2.2 | 2.5 | 2.8 | |
| Seek advice from family/friend | 1.2 | 2.2 | 0.8 | 0.5 | $\chi^2(6, 1906)=10.8$, $p=0.095$ |
| How important that country introduces bowel screening % | | | | | |
| Very important | 60.1 | 56.4 | 59.2 | 64.8 | |
| Important | 29.8 | 32.0 | 31.9 | 25.5 | |
| Not sure | 8.7 | 11.3 | 7.3 | 7.6 | |
| Unimportant | 0.8 | 0.3 | 1.1 | 0.9 | |
| Very unimportant | 0.6 | 0 | 0.5 | 1.2 | $\chi^2(8, 1924)=28.9$, $p<0.001$ |

*9.3.19. Screening interest and perceived risk*

Table 9.20 shows that interest was high across all three groups. Among the control group and those given risk factor and screening information higher perceived risk was related to greater interest in screening. The relationship was not significant among respondents given risk factor information. A loglinear analysis was performed to determine whether the relationship between perceived risk and screening interest differed by group. The difference was of borderline significance ($\chi^2$=8.8, df=4, p=0.068) giving little support to the idea that the relationship between perceived risk and interest was different across the 3 groups.

**Table 9.20: Interest in screening by perceived risk and group**

| | Interest in screening | | |
|---|---|---|---|
| | Group 1 Control | Group 2 Risk factor information | Group 3 Risk factor and screening information |
| | n=648 | n=637 | n=660 |
| Perceived risk % | | | |
| Lower | 89.9 | 91.1 | 89.1 |
| The same | 95.2 | 91.1 | 93.0 |
| Higher | 91.4 | 96.0 | 98.8 |
| Significance per group | $\chi^2$(2, 635)=5.9, p=0.051 | $\chi^2$(2, 617)=2.6, p=0.271 | $\chi^2$(2, 634)=7.8, p=0.020 |

## 9.4. Discussion

This study had the key aims of determining whether a leaflet intervention could: i) increase knowledge about risk factors, ii) reduce the bias associated with family history and symptomatic status, and increase perceived risk in men and older people ii) increase interest in attending for screening and seeking medical attention for symptoms if necessary. The study also explored the impact of giving risk factor information in combination with screening information.

*9.4.1. Increasing knowledge of risk factors*

As predicted, the level of knowledge was low among the control group. The present study successfully increased knowledge about risk factors with participants in the intervention groups having significantly greater knowledge of bowel cancer risk factors compared to the control group. The pattern of results was similar in those given risk factor information only and those given risk factor and screening information, suggesting that giving information on potential screening procedures did not alter knowledge. Berry (2004, p. 126) concludes that the major reason why risk communications fail is because people simply do not understand the message. For example, there is some indication that women do not understand the meaning of terms and phrases that are commonly used in breast cancer prevention messages, such as 'risk factors' and 'at risk' (Roche et al., 1998). The current study suggests that the leaflet, "Bowel Cancer: The facts" was widely understood by the participants, randomised to receive it, as their awareness of bowel cancer risk factors was significantly greater than the control group.

These findings are encouraging because they suggest that knowledge can be increased in the population using relatively cheap materials. These results have the potential to have implications for the design of materials when bowel screening is introduced in the UK. It is assumed that by having a better understanding of the risk factors involved, individuals will be better able to make informed decisions about screening and other cancer preventative lifestyle changes.

Higher educational achievement was associated with greater knowledge. As predicted, participants high in dispositional optimism were more knowledgeable. Interestingly, this was also true among those in the control group suggesting that they may have been attentive to information on cancer risk in the past. Even when education was controlled, those higher in dispositional optimism were more knowledgeable. However, neither dispositional optimism nor education were found to moderate the effect of the leaflet.

*9.4.2 Relationship between comparative and absolute perceived risk*

The two measures of perceived risk were found to be significantly related, confirming previous work suggesting that there is some overlap in the constructs (Collins, Halliday, Warren, & Williamson, 2000; Lipkus et al., 2000). The association provides an internal validation of the two measures. A recent study concluded that the direct measure of comparative risk (as used in the present study) does not necessarily involve a comparison process and recommended that researchers use an indirect measure (asked using two questions 1) personal risk judgement and 2) risk judgement for the target group) in eliciting people's comparative risk judgements (Covey & Davies, 2004). Future work could develop this idea and perhaps explore how people answer direct comparative risk questions using 'think aloud' methodologies.

*9.4.3. Impact of risk factor and screening information on comparative perceived risk*

Comparatively optimistic beliefs were not eliminated in the two intervention groups. Both showed significant optimism biases with the mean for comparative perceived risk deviating significantly from the mid-point.

There was no overall effect of risk information on mean comparative perceived risk score. However, the intervention groups had higher proportions of comparative optimists and comparative pessimists, indicating that the intervention leaflets made respondents less likely to view their risk as 'the same' as average. A slightly similar effect could be seen in data from the UK FS Trial. When participants were required to rate their standing on two health behaviours (smoking and exercise) prior to rating their perceived risk, they were less likely to rate their risk as 'the same' than those asked to rate their risk before being asked about their standing on the two health behaviours (unpublished data). This suggests that getting people to think about risk factors polarizes perceptions of risk, that is people are less likely to see their risk as average and more likely to see it as either 'lower' or 'higher' than average.

With the exception of Kreuter and Strecher (1995) who provided participants with computer-generated individualised risk-feedback for a range of health risks, the present study is unique in describing whether an intervention reduced optimistic beliefs or increased pessimistic beliefs. Previous studies have only provided mean scores for comparative risk (Weinstein & Klein, 1995; Lipkus et al., 1999; 2003) and therefore do not allow one to fully understand the effects of the intervention. The logistic regression analyses revealed that those given risk factor information had significantly greater odds of being pessimistic. This finding is in contrast to the results of Weinstein and Klein (1995, Study 2) who found that presenting lists of risk factors to students actually increased optimistic bias. However, in the present study participants given risk factor and screening information combined had significantly greater odds of being optimistic. Thus it would appear that combining risk factor information with screening information leads to different conclusions about risk estimates.

Why should the intervention have made those given risk information significantly more pessimistic and those given risk and screening information combined significantly more optimistic? Considerable research indicates that threatening situations are most likely to evoke cognitive defences if few ameliorative actions are perceived (Janis & Feshbach, 1953; Leventhal, 1970; Folkman & Lazarus, 1980; Lazarus & Folkman, 1984). This would suggest that providing risk factor information in the absence of screening information would result in greater defensive denial e.g. comparatively optimistic beliefs. However, this was not found to be the case, and it seems that providing risk factor information without screening information can increase perceived risk. It could be argued that increasing pessimistic beliefs should not be regarded a successful intervention. However, given that pessimistic beliefs have increased without corresponding increases in worry or anxiety suggests it may not be a detrimental outcome. Providing screening information may increase people's sense of control and it is known that greater perceived control is associated with optimistic bias (Weinstein, 1987; Klein & Helweg Larsen, 2002). In the present study the belief that there are things you can do to control whether you get bowel cancer was stronger in the two intervention groups compared to the control group, but no stronger in those given screening information. This suggests that screening information did not increase comparative optimism solely through an enhanced sense of control.

It is interesting that this differential pattern of results has emerged for estimations of perceived risk but not for emotional impact. It suggests that providing screening information does make a difference but not in the way predicted. In some respects it was surprising the differential effect was achieved since all participants were told in the letter from their GP that a national bowel screening programme would soon be introduced.

### *9.4.4. Impact of the intervention on absolute perceived risk*

The absolute measure of perceived risk also showed no difference across the three groups, and the sample as a whole saw their chances of developing bowel cancer as 34%. This suggests a considerable overestimation of risk as the population risk for developing bowel cancer in the UK is 5% (Quinn et al., 2001). This overestimation may be a reflection of poor numeracy skills among respondents (see Black et al., 1995; Woloshin et al., 1999; Weinstein et al., 2004). Another explanation may be that in the UK, Cancer Research UK ran a campaign highlighting that one in three people will suffer from cancer in their life time. During the interviews conducted for Study 4 it was apparent that the figure one in three had stuck with many people, and they did not take into account the fact that bowel cancer is only one type of cancer and so their chances of developing it are actually less than one in three. The absolute measure had poorer completion rate (7%) than the comparative measure (2%) perhaps suggesting that people find absolute questions harder to answer. Weinstein et al., (2004) also found that around 10% of respondents skipped the absolute risk question. Given that people tend to greatly overestimate their absolute perceived risk and are more likely to miss these questions more than others, suggests that absolute measures may not provide the best means for assessing perceived risk.

### *9.4.5. Impact of the intervention on subgroups*

*Comparative perceived risk.* Analysing the target subgroups (men, older age group, no family history, few bowel symptoms) showed that optimistic bias was only reduced in the older age group (56-66 years) for those given risk information, but not in the other subgroups. This is somewhat surprising as the question asks participants to compare

themselves to "*others of the same sex and age*" so if participants were truly making social comparisons one would not expect this effect. Among those given risk factor and screening information, optimistic bias was not reduced in any of the subgroups.

The leaflet failed to reduce optimistic beliefs among men in either of the two intervention groups, indeed the opposite effect occurred. Men in both intervention groups had significantly greater odds of comparative optimism than men in the control group. It was feared that giving women information saying that being male increases ones risk may have led to more optimistic beliefs, however this was not found to be the case as women in the intervention groups were no more optimistic than the control group. In the group only given risk factor information, men and women had greater odds of pessimism than their counterparts in the control group. It was odd to find that in the two intervention groups, men were actually more comparatively optimistic than the control group. In the univariate analyses men were no more comparatively optimistic than women, which was the intended impact of the intervention. However, in the control group an unexpected pattern of results emerged with gender not showing a significant relationship with perceived risk, unlike in Study 1 when men were significantly more optimistic. This suggests some sort of oddity in the relationship between gender and perceived risk in the control group. It may be the case that in the logistic regression when men in the intervention groups were compared with men in the control group (the referent) they appeared to be more optimistically biased than they may have done if the control group had shown the expected pattern of result. It is acknowledged that this explanation is speculation and a further large-scale study would be required to confirm it.

In terms of age, the intervention was somewhat successful. The older age groups in both intervention groups were significantly more pessimistic, indicating that they acknowledged that their older age put them at greater risk. It is possible that the leaflet impacted in this way because there was a very clear bar graph showing the relationship between age and bowel cancer mortality. In piloting the leaflet this graph was frequently commented on, "*I think the diagram is brilliant.*" (Female, age 62 years 017), whereas the other facts in the leaflet did not elicit this response. The leaflet also contained a bar graph showing the relationship between gender and bowel cancer mortality. The visual impact of this graph is

not as impressive (see Appendix 15). Future research may benefit from further exploring different presentation formats.

Among those without a family history, the intervention failed to reduce optimistic bias and actually accentuated the effect in people given risk factor and screening information. The intervention increased pessimistic beliefs in those with no family history of bowel cancer, although the effect was of borderline significance in the group given additional screening information.

Optimistic bias was not reduced among participants with few bowel symptoms. Again, the bias was actually accentuated in the group given risk factor and screening information. Both intervention groups had greater odds of pessimism. The findings for symptomatic status are not entirely unexpected. Within the context of the study, it was difficult to convey a strong threat message about people still being at risk even if they had no symptoms when screening was not being offered to participants. But perhaps more importantly, an ethical requirement was to include a list of bowel symptoms within the leaflet and the advice that people should contact their doctor if they were concerned about their symptoms. This advice was also given in the participant letter and in the questionnaire after participants had indicated the presence of any bowel symptoms. Therefore it was very difficult to get across the message that people could still be at risk even if they did not have any symptoms when participants were repeatedly reminded that if they had any symptoms they should contact their doctor. This in part may explain why the intervention failed to reduce the bias associated with symptomatic status. In the future when screening is being offered it may be possible to make this point more strongly and reduce the optimistic bias associated with having few bowel symptoms.

*Absolute perceived risk.* The absolute measure of perceived bowel cancer risk did not reveal any impact of the intervention. Perceptions of absolute risk did not vary across groups for any of the targeted subgroups.

### *9.4.6. Emotional impact of risk information*

Risk information was found to have no adverse emotional effects whether given on its own, or with screening information. This suggests that people do not become overly worried or anxious when presented with risk information about bowel cancer. It was predicted that presenting risk information in combination with screening information would allay detrimental effects, however risk information given in the absence of behavioural advice did not result in fear. It is encouraging that a relatively cheap and simple leaflet intervention increased knowledge in this way, and more importantly did so without increasing worry about bowel cancer or anxiety.

### *9.4.7. Increasing interest in screening, help seeking and beliefs about the importance of screening*

It was predicted that providing simple risk factor information would increase interest in attending for screening when it becomes available and seeking medical attention for symptoms if necessary. There was no effect of the intervention on interest or seeking medical attention. What was surprising about the current sample was the extremely high levels of interest in screening across all three groups, even in Groups 1 and 2 who were not told what bowel screening may entail. For the sample as a whole 63% stated that they would definitely take up the offer if invited, and 29% said they would probably take up the offer. In the UK FS Trial pilot centres, only 52% said they would definitely take up the offer and 31% said they would probably take up the offer (Wardle et al., 2000). The present sample is significantly more affluent than the national average and this may explain the higher levels of interest as better off people tend to be more interested in health protective measures (Pill, Peters, & Robling, 1995; Lowry, Kann, Collins, & Kolbe, 1996). In one of the UK FS Trial centres, Glasgow, more affluent participants were found to be more interested in screening, but even amongst the most affluent quartile interest was not as high as in the present study (57% definitely, 29% probably interested; Wardle et al., 2004). It is possible that in the 8 years since the UK FS Trial data were collected, people have become more accepting of cancer screening and this may be reflected in the increased demand from the public for PSA testing for men and for breast screening to begin at age 40 (Weller et al., 2003). There is some evidence in support of this explanation from a recent

study by Frew, Wolstenholme and Whynes (2001) which assessed interest in bowel screening (both FOBT and FS) in 2769 adults aged over 25 years contacted through GP practices in the East Midlands and South Yorkshire. Frew et al. reported that 89% of participants were interested in having a bowel screening test. An additional factor influencing the high interest rates in the present study may have been that the letter participants received from their GP stated a nationwide bowel cancer screening programme would soon be introduced. In the UK FS Trial participants were told that a 'trial' was being carried out in their area. This difference may have led the participants in the current study to feel more confident in this new form of screening and therefore more interested. While the high levels of interest in bowel screening are excellent from a public health prospective, it means that it is difficult to detect any variance in interest across the three groups.

Given the high levels of interest in screening, one may question the practical benefits of trying to change risk perceptions. From an academic point of view the fact that presenting risk factor information made participants more comparatively pessimistic, and providing additional screening information made them more comparatively optimistic is intriguing. However, as Weinstein and Klein (1996) note, "the biggest gap in the research on this topic is the absence of information about the behavioural implications of optimistic biases." The present study would suggest that optimistic biases may have very little impact on bowel screening behaviour. Perhaps the most interesting result of the present study was that those given risk factor and screening information were more comparatively optimistic but were no less interested in attending screening. This finding challenges the major assumption of unrealistic optimism – that it undermines health protective behaviour. I believe the answer to this conundrum lies with the different types of comparative optimists that I described in Study 2. Briefly, 'active' optimists will take steps to reduce their risk and so maintain their optimistic beliefs, while 'passive' optimists are overly optimistic without due consideration to their own risk behaviours that may influence their vulnerability (Armor & Taylor, 1998). It is possible that in Group 3, despite failing to reduce the optimistic bias, 'active' or 'functional' optimism was increased. This is reflected both in their increased awareness of bowel cancer risk factors, and in their willingness to attend bowel screening. Further work is needed to understand the differences between active and passive optimists, and not least how one might measure these two different types. A further challenge will be to engage the

non-respondents to this survey who may represent the true unrealistic optimists. From a public health standpoint, harnessing optimism to make people's optimistic beliefs more warranted would seem an appealing goal if it increased people's health behaviour while simultaneously making them feel more positive about their health.

### *9.4.8. Optimistic bias in the control group – comparisons with Study 1*

As predicted, the control group showed a comparative optimism bias. The proportion of comparative optimists was considerably higher in the current study (25%) compared with Study 1 (16%) and Study 2 (17%). An important difference between the studies was the measure of comparative perceived risk. In Studies 1 and 2, the measure of comparative risk asked, *"Compared to other men and women of your age, do you think your chances of getting bowel cancer are: lower; about the same; higher?"*. The recommended measure of comparative risk, used in the present study, asks participants to compare themselves to people of the same sex and age. Helweg-Larsen and Shepperd (2001) conclude that the overwhelming evidence suggests that the closer, more similar, and more specific the comparison target, the less people are optimistically biased. The present study found higher levels of comparative optimism than Studies 1 and 2 suggesting that in this instance the wrong wording may not have had the predicted impact. However, because a different measure of comparative risk was used, comparisons with the results of Study 1 are very tentative.

The level of comparative optimism seen in the current study suggests a movement in beliefs towards those found in the US-based studies, e.g. 36% of adults older than 50 years regarded their risk of developing bowel cancer as lower than average (Lipkus, Rimer, Lyna et al., 1996). It is not clear why this should be the case. The sample in the current study included those aged 45-66 years making it a younger sample than Studies 1 and 2, and the inclusion of those aged 45-54 years may have led to more comparatively optimistic beliefs. Against this view is that even amongst those aged 56-66 years (a comparable age group to Studies 1 and 2), 23% thought their risk was lower than someone of the same sex and age. The current sample was significantly more affluent than the national average unlike Study 1 which was representative. It is possible that a more affluent sample would result in more comparatively optimistic beliefs, indeed the individual deprivation score in Study 1 was

significantly related to perceived risk such that more affluent participants were more optimistic. However, one cannot be certain of the influence of socioeconomic deprivation on perceived risk as Study 1 also found that the Townsend deprivation measure was unrelated to perceived risk. The greater number of comparative optimists in the present study adds weight to my speculation in Study 1 that the sample in Study 1 may be more likely to regard themselves as average because they were children during World War 2 and this cohort are generally considered as being more socially-minded and therefore more likely to regard themselves as no better or worse than anyone else. Because the current data were collected approximately 8 years later and included a younger age group than Study 1, it is possible that they have had more exposure to American ideals and culture and therefore diverge less from the US-based studies.

Grunfeld et al. (2002) found in a population sample of UK women, with a mean age of 47 years, that 17% believed their risk of developing breast cancer was lower than average, 76% thought it was about average, and 7% thought their risk was higher than average. These findings are very similar to the results of Study 1. The data described by Grunfeld et al. were collected in early 2000. These results suggest that perhaps there has not been a shift towards more optimistic beliefs in the UK, and that the findings in the present study are something of an anomaly. However, it should be noted that the Grunfeld et al. study was only based on women and we saw in Study 1 that women are less optimistic than men. Therefore it is not clear whether men and women have become more optimistic in their comparative risk judgements in the past 8 years or whether this is only true for this specific sample.

In the subgroup analyses of the control group, the results were not as predicted from Study 1. Men and the older age group were not found to be more comparatively optimistic. In Study 1 the effect of age was small, and it may be the case that a larger sample size is required to detect such a subtle difference. The effect of gender was more pronounced in Study 1 and it is not clear why gender did not show a significant relationship with perceived risk in the present study. The influence of family history and symptomatic status was the same as in Study 1, with those with a family history and more symptoms reporting fewer comparatively optimistic beliefs.

*9.4.9. Limitations*

There are of course many limitations to this study. The study used a between-subjects design to explore the impact of risk factor information as have previous studies (e.g. Weinstein & Klein, 1995). A much stronger design would have been to use a within-subjects design to ensure that any differences were the result of the intervention and not due to variation between the groups. It was decided not to use a repeated measures design because follow-up rates tend to be poor, and it is difficult to give people good reasons for why you are asking them all the same questions again. The randomisation process successfully eliminated any chance differences between the three groups with the exception of subjective health which was statistically controlled in the logistic regression analyses. A second limitation was that in order to provide a rationale for the study to participants, all participants were informed that a nationwide screening programme would be introduced in the next few years. It is likely that this information diminished the effects of providing additional screening information in Group 3. However, a different pattern of results was seen for those given additional screening information compared to those only given risk factor information suggesting that it did have an additional impact. The response rate to the questionnaire was 62% which is comparable to the 61% in Study 1 and other primary care surveys (e.g. Walsh, 1994), but this means there is a substantial group whose risk estimates and reactions to risk information are unknown. One way to get a more accurate estimate of population levels of perceived risk would be to assess perceived risk in an Office of National Statistics Survey (ONS). However, even using this approach response rates are typically between 67-71% (Wardle, Rapoport, Miles, Afuape, & Duman, 2001; Sanderson, Wardle, Jarvis, & Humphries, 2004; Miles, Waller, Hiom, & Swanston, in press) which does not represent a significant increase in response, and given the expense of using the ONS survey the benefit may not outweigh the additional cost. The study was also limited in that it was not representative of England and Wales in terms of neighbourhood-level deprivation. However, it is unique in looking at the impact of risk information in a population sample, even if they were slightly more affluent than the national average. It may have been useful to ask participants how reliable or trustworthy they found "Bowel cancer: The facts", as other studies have done (Lipkus et al., 1999). But, given that the intervention groups were significantly more aware of the risk factors for bowel cancer suggests that they believed the information they read in the leaflet.

### *9.4.10. Conclusions*

The information leaflet, "Bowel cancer: The facts" was successful in increasing knowledge about bowel cancer. Providing information such as this when bowel screening is introduced in the UK therefore has the potential to increase informed decision-making as people will have a better understanding of the risk factors and whether they should consider screening. Further, the leaflet was able to increase knowledge without causing people to become more worried about bowel cancer or more anxious.

Although the intervention successfully changed beliefs about that nature of the condition, the impact on personal risk judgements was not so clear. The intervention failed to eliminate optimistic bias in either of the two intervention groups: those given risk factor information were more pessimistic, and those given risk factor and screening information were more optimistic. However, interest in bowel screening was uniformly high across both groups suggesting that being pessimistically or optimistically biased did not influence behavioural intentions. Future work should consider differences between active and passive optimists and on ways of harnessing optimism to make people's optimistic beliefs more warranted.

# CHAPTER 10

## Conclusion

The aim of the present series of studies was to understand how personal risk for bowel cancer is perceived. A review of the literature found little empirical work exploring perceptions of risk for cancer outside of breast cancer research. Given that nationwide bowel cancer screening is soon to be introduced in the UK it is important that the population are sufficiently motivated to participate in this new form of screening. Perceived risk is regarded as being the 'motivational engine' behind many preventive behaviours so it is vital we understand perceptions of bowel cancer risk so that strategies can be developed to maximise participation. The research in this thesis has taken a first step in understanding the factors related to perceived bowel cancer risk and whether perceptions of risk can be changed.

### 10.1. Summary of main findings

1. What are people's perceptions of risk for bowel cancer?

Unrealistic optimism has been found for a diverse range of illnesses and safety hazards (Weinstein, 1980; 1983; 1984; 1987), and so it was predicted that an optimistic bias for bowel cancer would be seen in a UK population sample. All three studies quantitatively assessing comparative optimism (Studies 1, 2, and 6) found an optimistic bias. Studies 1 and 2, using data from the UK FS Trial, found lower levels of optimism than had been seen in US-based studies (e.g. Blalock et al., 1990; Lipkus, Rimer, Lyna et al., 1996). Slightly higher levels of comparative optimism were detected in the control group of the leaflet intervention study, Study 6. This may indicated that the UK population are becoming more comparatively optimistic, however this suggestion is tentative, and it is not clear whether the differences between levels of optimism between the UK FS Trial and the control group

in Study 6 are significant. Future research might consider whether the UK population is becoming more comparatively optimistic as information about prevention and screening tests becomes more widespread. Overall, people in the UK do show an optimistic bias in estimating their chances of developing bowel cancer.

2. Are certain subgroups more likely to be comparatively optimistic about their bowel cancer risk?

Certain subgroups are more likely to see themselves at lower risk than average of developing bowel cancer. Study 1 found that being male and older were associated with lower perceived risk. Having a family history of bowel cancer, poorer subjective health, more symptoms, and higher levels of anxiety were all associated with increased perceived risk of bowel cancer. Smokers and non-exercisers perceived their risk as higher. Some of these findings were replicated in the control group of the leaflet intervention study, Study 6; others e.g. the effects of age and gender, were not. The sample size in Study 1 was more than 17 times that of the control group in Study 6, and so the results of Study 1 are interpreted as being more reliable. Therefore, certain subgroups of the population are more likely to be comparatively optimistic, and it is possible that these groups could be targeted in public-health education to ensure that their comparatively optimistic beliefs do not prevent them from engaging in health protective behaviours.

3. Do perceptions of risk for bowel cancer relate to clinical endpoints?

Perceived bowel cancer risk was modestly related to findings at FS screening. This result is in line with previous work using algorithmic estimates of actual risk (Lipkus et al., 1996; Woloshin et al, 1999; Weinstein et al., 2004). This suggests that people may be taking certain risk factors into account when estimating their risk (e.g. smoking, family history), but the small effect size may reflect their failure to acknowledge other risk factors. People are therefore not particularly accurate in making personal risk judgements about bowel cancer and may require guidance to become better informed about the health risks they face.

4. To what extent does Weinstein's (1984) five factor framework 'explain' the variance in perceived risk of bowel cancer?

Weinstein's (1984) five factor framework (actions and behaviour patterns, heredity, physiology/physical, psychological attributes, and environmental factors) was found to explain little of the variance in perceived risk of bowel cancer using the UK FS Trial data. Only 8% of the variance in perceived risk was explained using measures taken from the UK FS Trial to operationalise the five factors. A significant weakness of Study 3 was the limited number of measures available to try to 'capture' each of the five factors. Study 4 took a qualitative approach to examine how people conceptualise their personal risk of bowel cancer and the factors they use in estimating their risk in an attempt to better understand why Study 3 had failed to explain more than 8% of variance in perceived bowel cancer risk. The qualitative interviews in Study 4 confirmed the usefulness of the five factor framework in understanding people's reasons for their risk judgements, and revealed that diet was a frequently mentioned reason while environmental and psychological explanations were rarely expressed. Furthermore, it appeared that the type and level of experience of someone with cancer was influential in personal risk judgements. The findings from Study 4 guided the choice of the measures used in Study 5 which considered a broader range of items in operationalising the five Weinstein (1984) factors. The result was that 18.5% of the variance in perceived risk was explained, representing a significant improvement on Study 3. However, the five factors only explained around a fifth of the variance in perceived risk suggesting that additional processes – possibly non-conscious – may be important in furthering our understanding of perceived risk.

5. Can perceptions of risk for bowel cancer be changed?

The answer to this question depends on how perceived risk of bowel cancer is measured. Study 6 found that using the comparative measure of perceived risk there was a differential impact of providing risk information with and without screening information relative to the control group. Those given risk factor information had significantly greater odds of being comparatively pessimistic compared to those in the control group. Those given risk factor and screening information were significantly more comparatively optimistic relative to the control group. A key objective of Study 6 was to reduce comparative optimism among

targeted subgroups (those with no family history, those with few symptoms, men and older people). Comparatively optimistic beliefs were not reduced in a single subgroup. However, comparatively pessimistic beliefs were increased in all of the subgroups for those given risk factor information only, and for older people and people with few symptoms in those given risk factor and screening information.

Using a numeric, absolute measure, people in the two interventions groups perceived their risk of bowel cancer as the same as those in the control group. The intervention therefore failed to change perceptions of risk as assessed by an absolute measure.

**Overview**

Overall, it would seem that people in the UK are not particularly accurate in judging their risk of developing bowel cancer. This general inaccuracy has been seen at the group level, and at the individual level when subjective risk was linked to actual risk. It also appears to be the case that certain subgroups are more likely to express comparatively optimistic beliefs about their chances of developing bowel cancer. Therefore there is potential for such subgroups to be targeted through public-health education to make them more aware of their risk status. However, this thesis has shown that merely providing people with a leaflet describing the main risk factors for bowel cancer is not sufficient to reduce optimistic bias amongst these subgroups. The leaflet successfully increased awareness of the risk factors, but interest in screening was not increased among those receiving the risk factor information. Despite the failure of the leaflet intervention to reduce optimistic bias or increase interest above the high levels found in the control group, it is at least encouraging that people were better informed after reading the leaflet, and it did not have an adverse impact on psychological wellbeing. Therefore materials such as these may be useful in helping people make informed choices about whether to undergo screening when it is introduced.

Weinstein's (1984) five factor framework is useful in organising the factors influencing perceived risk. However, using people's standing on the five factors to explain the variance in perceived risk showed that only around one fifth of the variance was explained. This suggests two conclusions. Firstly, the five factors are important in understanding people's

explanations for their risk estimates and the fact that 18.5% of the variance was explained confirms this. The second conclusion is that over 80% of the variance in perceived risk remains unexplained and further work is required to explore the contribution of these other influences. It is possible that by better understanding the 'other' influences on perceived risk, attempts to modify personal risk perceptions may be more successful.

## 10.2. Implications for theory

In thinking about the determinants of perceived risk, I started from a rationalist, cognitive perspective and thought that Weinstein's (1984) five factor framework, based on people's explanations of their risk judgements, would provide a useful model in explaining the variance in perceived risk. In Study 3 I found that the framework only explained 8% of the variance and concluded that this was because the factors had been badly operationalised using the limited measures available from the UK FS Trial data. The qualitative interviews in Study 4 provided important information on how to better operationalise the framework. However, Study 5 showed that less than a fifth of the variance was explained using a broader range of measures to capture the five factors. I therefore believe that people's own explanations for their risk judgements can tell us only part of the picture of the true determinants of perceived risk. It is possible that people are not able to verbalise the thought processes involved in estimating their risk. Nisbett and Wilson (1977) argue that there may be little or no direct introspective access to higher order cognitive processes, such as making personal risk estimates. Instead, people's explanations are based on a priori, implicit causal theories. Thus people mention factors which can be grouped into the five Weinstein factors, but this does not necessarily mean these factors explain their risk judgements. I became increasingly aware of people having little or no direct introspective access to the processes involved in estimating their risk during the qualitative interviews carried out in Study 4. I was interested in whether people were answering the comparative risk question in a truly comparative way or whether they were answering it in absolute terms. When I asked people how they answered the question, e.g. "*did you think about other people of the same sex and age as you?*" they were mostly unable to provide an answer, but the fact that they had mentioned diet, family history etc. suggests, implicitly, that comparative processes were involved.

A greater understanding of the determinants of perceived risk may be obtained by exploring the sub-conscious or experiential processes involved in making a risk judgement. This would involve considering affective processes[35]. One candidate is emotions, and several studies have shown that people in good moods make more optimistic judgements while people in bad moods make pessimistic judgements (e.g. Johnson & Tversky, 1983). Furthermore, Kahneman and colleagues have noted that jurors' decisions cannot be understood from an economic preference perspective but can be understood in terms of 'gut reactions' (Kahneman & Ritov, 1994; Kahneman, Schkade, & Sunstein, 1998; Kahneman, Ritov, & Schkade, 1999). In the present thesis the only affect measure studied was state anxiety. Future work should examine the impact of other aspects of mood on perceptions of risk. Subconscious processes involved in making risk estimates may be accessed under experimental conditions by asking participants to make risk judgements while carrying out a concurrent cognitive task, thereby suppressing cognitive processes and potentially tapping into the subconscious, 'gut-reaction' level of processing. This is an avenue for future work in understanding the determinants of perceived risk.

The second main finding in terms of implications for theory was the failure to debias optimistic beliefs for a relatively unfamiliar hazard. Even when the targeted subgroups were examined, there was no evidence that optimistic beliefs had been reduced, indeed the intervention served to increase optimistic beliefs in certain instances. These findings replicate the series of studies by Weinstein and Klein (1995) who also failed to reduce optimistic beliefs. The present thesis is one of the few pieces of research that has considered whether the intervention worked by reducing the proportion of people with optimistic beliefs and shifting them to perceive their risk as average, or by increasing the proportion of people with pessimistic beliefs i.e. shifting those who see their risk as average to perceiving their risk as higher than average. Thinking about the impact of manipulations on perceptions of risk in this way is more revealing than simply reporting the mean score in comparative perceived risk.

[35] Kahneman (2003) even suggests that affect should join representativeness and availability in the list of general-purpose heurtistic attributes.

It was predicted that giving people risk information would lead to greater interested in bowel screening, however there was no effect of the intervention on interest; high levels of interest were reported even amongst the control group.

An intriguing finding from the study was that people receiving both risk factor and screening information became more comparatively optimistic yet, surprisingly were no less interested in bowel screening. This leads to the conclusion that optimistic beliefs may not have the detrimental impact on bowel screening that some theories predict. However, it should be borne in mind that these comparative optimists had read a leaflet on bowel cancer and so they may in some ways be regarded as more 'active' optimists. Possibly only the 'passive' optimists would be less interested in screening.

In thinking about perceived risk and behaviour, it is important to remember that perceived risk provides only one pathway to understanding health behaviour. It is perhaps not surprising therefore that the differential impact of the intervention on perceptions of risk failed to have a differential impact on behavioural intentions.

### 10.3. Implications for practice

Because bowel screening is to be introduced in the UK in April 2006, this thesis is timely and has several implications for practice. It has identified that people are poor judges of their risk status, and in particular men, older people, those without a family history of bowel cancer, and those who feel well and have few symptoms are more likely to regard their risk as lower than average. Health professionals should be made aware of these facts and should particularly emphasis the benefits of bowel screening to these groups.

Previous work has shown that the UK population has a low level of knowledge about bowel cancer (McCaffery et al., 2003). Study 6 showed that it was possible to increase knowledge of bowel cancer using relatively cheap materials and without increasing anxiety or worry about bowel cancer. These results therefore have the potential to influence the design of materials when bowel screening is introduced in the UK.

## 10.4. Limitations

*Response rate*

There are several limitations to the present thesis. The quantitative studies had response rates of around 61% and while this level of response is similar to that achieved by other primary care surveys (Walsh, 1994), it means that we know little of the risk perceptions for the substantial proportion of the population who did not respond. As I discussed in Study 2, it is possible that so called 'active' optimists were more likely to respond to the questionnaires in this thesis and the truly 'unrealistic' or 'passive' optimists did not participate because they felt bowel cancer was not relevant to them. It is also not clear how the non-respondents reacted to the risk information leaflet, and while I concluded that the leaflet showed no adverse impact on emotional wellbeing, it is possible that anxiety or worry may have been increased among the non-respondents.

*Measures*

A major advantage of the present thesis is the large sample sizes and the range of factors assessed. This approach comes at a cost because the measures are brief and as a result can be weak. Some of the measures were based on validated measures and some were based on items that had been used in previously published work. The most significant limitation of the measures used was that in Studies 1-3, the measure of perceived comparative risk asked, "*Compared to other men and women of your age, do you think your chances of getting bowel cancer are: lower; about the same; higher*". This is not the recommended measure of comparative risk as participants should be asked to compare themselves to people of the same sex and gender. The correct question was used in studies 4-6. Helweg-Larsen and Shepperd (2001) conclude that the overwhelming evidence suggests that the closer, more similar, and more specific the comparison target, the less people are optimistically biased. Given the levels of comparative optimism in the data from the UK FS Trial were actually less than those in the control group of Study 6 using the appropriate question, it seems likely that the wrong wording used in the Trial may not have had a great impact.

Other measures used in this thesis were based on single item measures e.g. *"Do you take regular exercise each week? Yes; no"* which is not a particularly accurate way to assess activity. In Study 6 I attempted to use a validated measure of physical activity (e.g. Baecke Questionnaire of Habitual Physical Activity, Baecke, Burema, & Frijters, 1982; International Physical Activity Questionnaire, Booth, 2000) but found it impossible to find a scale brief enough to be included. I therefore developed my own measure based on these other measures but brief enough to ensure the questionnaire did not become overly long. A consequence of this is that the validity and reliability of the measure is unknown, although the face and content validity were good. The same problems are true of the measures I used to assess diet in Study 6.

In Study 6 I only had a measure of interest in screening and not a measure of actual behaviour. Although intentions are known to predict cancer screening behaviour it is not clear what the impact of the intervention would be on behaviour. In reviewing the data from the UK FS Trial it was also only possible to assess the relationship between perceived risk and interest in screening. The two-stage recruitment process (only participants who indicated that they were interested in screening were entered into the Trial) meant that there was reduced variability in the perceived risk measure and so there was not a significant relationship with screening attendance (Sutton et al., 2000). Future studies could profitably explore the relationship between perceived risk and attendance at screening.

*Design*

In looking at the correlates of perceived risk only cross-sectional data were available and so cause and effect cannot be determined. It seems unlikely that people's risk perception would influence their response to a smoking or family history question but it remains a possibility using this design.

A stronger design for Study 6 would have been a within-subjects design to ensure that any differences were the result of the intervention and not due to variation between groups. This would have allowed the examination of the impact of the intervention within the same individuals and would have detected whether risk perceptions could be truly 'changed'. Future research could explore the impact of the intervention using a within-subjects design

although given that in Study 6 the randomisation process was successful the same pattern of results would be expected.

A further limitation of the design of Study 6 was that in providing a rationale for the study to participants, all participants were informed that a nationwide screening programme would be introduced in the next few years. It is therefore difficult to assess the additional impact of giving screening information.

*The approach of 'explaining' the variance in perceived risk*

As discussed in the section on implications for theory, I considered only the cognitive, rational determinants of perceived risk which were accessible to self-report. I therefore may have missed a whole class of 'other' determinants of perceived risk which are not accessible via introspection.

In testing the Weinstein (1984) framework I took a tangential approach and looked at whether people's standing on the five factors explained the variance in perceived risk. This is a different approach to previous work using Weinstein's five factors which has simply asked people to explain the reasons for their risk estimate. It is also acknowledged that it may be almost impossible to ever fully operationalise Weinstein's framework because factors such as psychological attributes are so broad that they could include almost anything. It is also acknowledged that trying to explain people's risk judgements based on their standing on various factors assumes that people are aware of the causes of bowel cancer, and as it has been repeatedly pointed-out people's knowledge of bowel cancer is very low in the UK (McCaffery et al., 2003). Given this general lack of awareness on the subject of bowel cancer it is perhaps not surprising that so little of the variance in perceived risk is explained by considering people's standing on certain factors.

*Samples*

Studies 1 and 3 used samples which were fairly representative of the demographic profile of the population of England and Wales. However, Studies 2, 5 and 6 had samples which were unrepresentative and significantly more affluent. Thus the conclusions drawn from

these studies cannot be generalised to the population as whole. It is also worth considering that throughout this thesis the samples have been based on older adults aged 45-65 years and so the findings are not generalisable to younger or older age groups. Studies 5 and 6 also contained a disproportionately low number of ethnic minority groups, with 98% of the sample being classifying themselves as white. Therefore the findings may only be generalisable to affluent, white groups.

## 10.5. Future work

The present thesis has raised a number of questions which may be addressed in further research. One area would be to further explore the concept of 'active' and 'passive' optimists. It seems an appealing idea to attempt to make people's optimistic beliefs more warranted by encouraging them to engage in health protective behaviours rather than attempting to 'scare' them into doing it. In this way we would be trying to increase the number of 'active' optimists. The difficulty would lie in trying to access the more 'passive' optimists who by their nature may be less interested in completing a questionnaire or taking part in an intervention about an illness they do not feel they are likely to develop.

Future work needs to consider the measurement of perceived risk. There are significant disadvantages to using absolute measures and it is not clear how people answer comparative risk questions. A recent study found that a 2-point measure of perceived risk (e.g. *"Do you think it's likely or that it's unlikely that you would get Lyme disease in the future?*) was more predictive of vaccination behaviour than other response scales – a 6-point, percentage scale and a 5-point, verbal category scale (Brewer, Weinstein, Cuite, & Herrington, 2004). This may provide a more natural way for people to think about risk as they tend to think it will either happen or it won't (in some ways explaining the 50/50 blip – respondents' tendency to use 50% when they believe it might or might not happen (Fischhoff & de Bruin, 1999)) and not on a population basis. This 2-point measure warrants further examination.

Future work could also assess whether Weinstein's (1984) five factor framework explained more of the variance in perceived risk for other types of cancer or other diseases. It is

possible that for diseases, such as heart disease, that the population have a greater knowledge of, the Weinstein factors may explain more of the variance.

Another avenue for future research would be to explore how people draw personal conclusions from generic risk factor information and to better understand why people given both risk factor and screening information become more comparatively optimistic. This could be explored by doing interviews using the 'think aloud' methodology whereby people would be asked to read the leaflet and 'think aloud' about how this makes them feel about their own personal risk. The impact of screening information on risk perception might also be explored using more experimental type studies under controlled conditions to identify what causes people to feel more comparatively optimistic. Self-efficacy may provide one explanation.

When bowel screening is introduced in the UK it may be possible to develop materials that better emphasise to people that the absence of symptoms is no basis for complacency. In Study 6, participants were repeatedly reminded that if they had bowel symptoms they should contact their GP, thus reinforcing the idea that someone should only be concerned if they are experiencing symptoms.

In general, the leaflet could be developed as a method of informing people about bowel cancer and bowel screening in an effort to ensure that people make informed decisions. Furthermore if we are able to communicate effectively to the public about the risk factors for bowel cancer and steps they can take to reduce their risk we will have contributed to the public 'engagement' with health promotion and disease prevention called for in the Wanless Report (2002).

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# APPENDICES

Appendix IV: Letter sent to participants in Study 4.


ENDOSCOPY UNIT
St Mark's Hospital
Northwick Park
Watford Road
Harrow
Middlesex
HA1 3UJ

«Title» «First_Name» «Surname»
«Address1»«Address2»
«Address3»
«Address4»
«Postcode»

Dear «Title» «Surname»

**Re: Preventing bowel cancer by screening**

A nationwide bowel cancer screening programme for men and women around the age of 60 will be introduced in the near future. This will be similar to the breast screening programme which already exists for women.

Before this programme starts our colleagues at University College London would like to interview some people about their interest in screening programmes for cancer. This will help us to launch the bowel cancer screening programme in the best way possible.

An information sheet is enclosed to tell you more about what is involved. Please read it carefully. Over the next few weeks, one of the researchers may telephone you to see if you are willing to be interviewed. You will be able to say no if you do not want to take part.

If you would rather not be contacted about the study, please complete the slip at the bottom of this letter and return it in the stamped, addressed envelope provided in the next week. If you would like further information on the study, you can call Ms Katie Robb on 020 7679 6644. She will be happy to talk to you about the study.

If you decided not to take part in the study, your current or future medical care will not be affected in any way.

Yours sincerely,

Maggie Vance
Consultant Nurse

✂----------

**I would rather not be contacted by researchers**

Name:_____

Address:_____

Appendix V: Information sheet used in Study 4.

ENDOSCOPY UNIT
St Mark's Hospital
Northwick Park
Watford Road
Harrow
Middlesex
HA1 3UJ

Date: 18th of September 2003-09-18

## Preventing bowel cancer by screening

---

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your friends and relatives if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

**Why have you been chosen?**
A group of patients at your GP practice between the ages or 60-64 years have been randomly selected to take part in this study. We are interested in finding out about people's views on screening programmes for cancer and we would like to invite you to take part in an interview.

**What is the purpose of the study?**
A nationwide bowel cancer screening programme is to be introduced in the UK in the near future. As part of our commitment to achieving a high quality service we would like to contact you and ask a few questions about your views on cancer risk and cancer prevention. If we have a clear understanding of what people think about cancer then we will launch the bowel screening programme in the best way possible.

**What will the study involve?**
The study will involve a one-to-one interview with a researcher. The interview will last about an hour and will cover your views about cancer risk and interest in preventing cancer. If you agree, the interview will be tape recorded so that the interviewer does not have to make notes during the interview and can concentrate fully on listening to you. You can ask for the tape to be stopped at any time. The interview will take place at your home or at the research office, whichever you prefer and all travel expenses will be refunded.

**Confidentiality**

All information that is collect about you during the course of the research will be kept strictly confidential. All tapes will be kept in a locked cabinet in the research office and will only be accessible to members of the research team. Your name will not be on the tape. Notes will be taken from the tape-recording of the interview but your name will be removed. We will not be able to identify any individuals from the recordings. Once notes have been taken, the tape will be destroyed. This process will take us between 2 and 8 weeks.

**Do I have to take part?**
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the standard of care you may receive now or in the future.

**What do I do now?**
Please think about the study. Our researcher will contact you to find out if you are interested in taking part. She will be able to answer any questions that you have and you can tell her whether or not you wish to take part in the study.

**Further information about the study**
If you would like to obtain further information about the study please contact:

**Ms Katie Robb**
**Health Behaviour Unit**
**University College London**
**Tel:**

This study is funded by Cancer Research UK and the Medical Research Council. It is intended that the results of the research will be published in a medical journal in about 2-3 years time. It is important to point out that no volunteers included in the research will be able to be identified from any report or publication. However, if you would like a copy of the published results of the research peoples contact us at the address given above and we will be happy to send them to you.

## The aim of this research is to improve screening services for men and women in the future

Appendix VI: Consent form used in Study 4.

## Preventing bowel cancer by screening

### Consent Form - Interviews:

*Please complete the following:*

| | *Please cross out as necessary* |
|---|---|
| Have you read the information sheet about this study and had the opportunity to ask questions? | Yes/No |
| Have you received satisfactory answers to all your questions? | Yes/No |
| Have you received enough information about this study? | Yes/No |
| Do you understand that you are free to withdraw from this study at anytime without giving a reason, and that your present or future medical care will not be affected? | Yes/No |
| Do you agree to take part in this study? | Yes/No |

---

***It would be easier for me to audiotape the interview. If you are not happy to be taped, I will take notes instead.***

| | |
|---|---|
| I give consent to be audio taped | Yes/No |
| I understand that these audiotapes will be destroyed when the study is complete | Yes/No |

Signed..... Date.....

(Name in block letters).....

Signed (Researchers):..... Date.....

(Name in block letters).....

**Contact information:**
**Katie Robb, Health Behaviour Unit, 2-16 Torrington Place, London WC1E 6BT**
**Tel: 020 7679 6644 E-mail: k.robb@public-health.ucl.ac.uk**

Appendix VII: Topic guide used in Study 4.

**BELIEFS ABOUT CANCER**

OBJECTIVES

- To assess perceptions of comparative risk for bowel cancer To explore reasons given for risk judgements
- To explore how these reasons relate to experience and personal behaviour
- To examine beliefs about causes of cancer (both general and specific types)

INTRODUCTION

- Introduce study; confidentiality; timing; no right or wrong answers; recording

**1 BACKGROUND**

- Age and marital status
- Education
- Employment status

**2 COMPARATIVE RISK JUDGMENTS**

- Bowel/colorectal cancer

**3 REASONS FOR JUDGMENTS**

- Bowel/colorectal cancer

*Probes, "why is that?" "Can you tell me a little more about that....?" "What makes you say that?" "Are there any other factors that influenced your judgment?" " Could you explain what you mean by....." "This may sound like an obvious question, but why....." "I just want to make sure I've really understood you. What was it exactly that.....?"*

**4 EXPERIENCE**

- Know anyone who has or has had cancer?
- Someone they know well?
- Did they tell you much?
- If family history, do they feel particularly at risk? Cancer in general or specific?

**5 CAUSES, CONTROL AND PREVENTION**

- Causes of cancer – some people get it others don't, why? General and specific
- Factors that increase and decrease risk. General, but also bowel.
- Preventibility
- Vulnerability and behaviour change

**6 SCREENING**

- Heard of bowel screening

- Interest

## 7 COMPARATIVE RISK JUDGMENTS

- Bowel/colorectal cancer

## 8 CONCLUSION

- Any thing else they would like to say?
- They will be contacted shortly for screening
- Thank them for valuable input

Appendix VIII: Coding manual and coding sheet used in Study 4.

# Beliefs about bowel cancer
# Content analysis: Coding manual

**Introduction**
A sample of older men and women aged around 60 years were interviewed about their beliefs about bowel cancer and cancer in general.
The aims of the interviews were as follows:

1. To explore how people perceive their risk of getting bowel cancer, cancer in general and breast/prostate cancer and the reasons why.
2. To understand how people answer comparative risk perception questions and whether or not they engage in social comparisons.
3. To examine beliefs about prevention and the causes of cancer.
4. To explore whether cancer is seen as one disease or a collection of many.

*Please note that a second aim of the interviews was for participants to evaluate materials developed to inform people about bowel cancer screening. The data from this section of the interview is not of interest in the current analysis and should be ignored for the purposes of coding.*

All twenty interviews were conducted by the researcher (KR). One interview was conducted over the telephone at the wish of the participant. Three interviews were conducted in the Health Behaviour Unit, University College London and the remaining sixteen interviews were carried out in the participant's own home. All interviews were tape-recorded and then transcribed. There is one transcript for each participant interviewed.

These interview will be examined using content analysis.

**Instructions to coders**
Please read through each transcript and then using this coding manual and the coding sheet, identify and 'code' the themes from the transcript onto the coding sheet. Please use a separate coding sheet for each transcript.

The coding sheet lists the various themes or 'codes' that address the research aims listed above. Each theme is concerned with a slightly different aspect of the overall research aims. Within the transcript a theme is identified as a unit of text which may be one word, several words, a sentence or several sentences that conveys the same meaning. The coding manual has attempted to list all possible themes that might appear in the transcript that are relevant to the study goals. If there is a belief expressed by the participant that is not listed but that is relevant to the study aims please make a note of this in the space provided.

Your job as coder is to read through the transcripts and for each one, code for the presence of the different themes. You are coding for meaning so it doesn't matter if the belief is expressed in different words to that written in the coding manual as long as the meaning of the belief in the transcript is conceptually similar. For example.....

Before starting please take time to familiarise yourself with the coding sheet by reading through it several times. This will allow you to become aware of themes that you should be looking out for when reading the transcripts. When you have finished coding a transcript you should read through the coding sheet one last time to ensure you have coded all relevant themes.

Only code the issues discussed in the interview that are related to the themes described below.

## CODING MANUAL

Section 1: Risk judgment

**About the interview:** Participants were given a sheet which asked them to indicate their comparative risk for 1) cancer in general 2) bowel cancer 3) breast cancer (for women) and prostate cancer (for men). They were then asked to indicate their absolute risk for getting bowel cancer on a verbal scale then on a numeric scale. For the purposes of this analysis we are only interested in their responses to the comparative risk questions. In some cases participants verbalised their responses to these questions and in others they just marked them on the sheet. Their response sheet should be attached to the coding sheet and you should transfer their answers onto the coding sheet.

Section 2: Reaction to risk question

We are also interested in finding out how participants initially respond to the comparative risk question. Therefore, please indicate any remarks or initial reactions participants have.

Section 3: Reasons for beliefs/causes

**About the interview:** Participants were asked an open ended question about the things they thought about when answering the comparative risk questions. The aim is to code the reasons they give for their risk judgments, why they see their risk in that way. Participants were then asked about what they thought the causes of cancer were and whether they thought it could be prevented. You will notice in the transcripts that there is some overlap between the reasons they give for their personal risk judgement and what they see as the causes of cancer. We would like you to distinguish between the two when you are coding the transcript. That is we would like you to code the reasons they give for their personal risk judgements under the column 'me' and to code more general beliefs about the causes of cancer and how it can be prevented under 'people in general'.

See Table 1 below for examples.

Table 1

| 'Me' | 'People in general' |
|---|---|
| "I've got good bowel movements" | "I assume if you don't have enough roughage and faeces don't pass at a regular time and maybe having a build-up...." |
| "I try and have a healthy diet, which it, a balanced diet, fruit everyday and vegetables everyday. That sort of thing. Very little of stuff that's supposed to be bad for you, as much as possible anyway." | "I think, bowel cancer can sometimes be caused by poor diet and the waste matter you know lying too long in your system and things like that." |
| "I'm feeling fit and healthy so therefore I think there's less risk of it." | "Because I think, um, bowel's obviously a muscle and the way it operates. Keeping fit and healthy gives it the chance to keep healthy itself rather than relax and not do anything." |
| "Yes, I've never smoked, never smoked. As I say, I've always been active anyway. I've always walked a lot." | "I think perhaps if you get older it might be more of a risk perhaps" |

The coding sheet also has separate columns for responses relating to cancer in general, bowel cancer, breast cancer and prostate cancer. If it is not clear what type of cancer they are talking about then code under 'cancer in general'. Also if they are talking about a specific type of cancer such as lung cancer code under 'cancer in general'.

Within each belief please distinguish between whether participants see the factor as increasing or decreasing risk. In some cases they may mention a factor as both increasing and decreasing risk e.g. 'eating a healthy diet can reduce risk' should be coded under 'Diet decreases risk'. The same person may also state 'not eating enough fibre increases risk' and this should be coded under 'Diet increases risk'.

**Family history/genes:** Please indicate if participants mention having a first degree relative, write in the space provided who the relative is, if the relative has bowel, breast or prostate cancer indicate by ticking the relevant box. If the relative has a cancer other than bowel, breast or prostate tick the 'cancer in general' box and write the particular type in the space provided.

**Health behaviours:** The diet category should include beliefs about healthy eating (e.g. eating fruit, vegetables and fibre) or unhealthy eating (e.g. high fat diet). The diet category should not include specific references to chemicals/preservatives that may be in food or comments about containers of food (e.g. tin). These beliefs should be coded

under the Environmental section. Similarly comments about organic foods should be coded under the Environmental section.

Under 'Taking medications' exclude beliefs about HRT as this should be coded under 'Hormonal factors' in the Physical wellbeing theme.

Having had or having checks should include any beliefs about mammography or cervical screening, any bowel checks whether diagnostic or screening and any other medical checks that participants mention.

**Physical wellbeing:** 'Other health concerns' should include any beliefs participants have about health conditions other than cancer. For example they may have a strong personal or family history of heart disease which makes them feel more vulnerable to heart disease and therefore feel they are unlikely to have or die from cancer. Also include beliefs about other health concerns compromising the immune system and therefore making someone more vulnerable to cancer.

**Psychological factors:** 'Mind/body' should include any beliefs about the mind having an influence over the physical state of the body e.g. positive thinking. 'Trigger' should include beliefs about something happening to someone that may have caused cancer e.g. a fall, a serious shock 'to the system', a bereavement, an illness, an accident etc.

Section 4: Social comparison

**About the interview:** After participants made their comparative risk judgments they were asked (either early on in the interview or near the end) how they answered the question, whether they thought about other people when they were answering the question. The aim of this question was to identify whether people engage in social comparison and actually think about their risk compared to others of the same sex and age. If they make any mention of thinking about other people when answering the question, please code as 'Engaging in social comparison'.

Section5: Experience

**About the interview:** In this section we are trying to identify how much exposure participants have had to cancer. Beliefs may have been elicited from specific questions on whether they have any friends or acquaintances who have had cancer or participants may just mention their experience spontaneously. Non-blood relatives should be coded under this section (e.g. spouses, spouses family).

Section 6: Model of cancer

**About the interview:** In this section we were trying to see whether people see cancer as one disease or whether cancer is seen as an umbrella term for many different diseases.

# Beliefs about bowel cancer
# Coding Sheet
**(please use in conjunction with the coding manual)**

Patient ID.....
Age.....
Gender.....

**1. Risk judgment**

*Tick the appropriate box if the transcript contained a reference to any of the themes listed below. Remember the wording does not have to be the same, you are coding for similar meaning.*

| Question | Cancer in general | Bowel cancer | Breast cancer | Prostate cancer |
|---|---|---|---|---|
| **1.1 Risk judgment** | | | | |
| • Below average | ☐ | ☐ | ☐ | ☐ |
| • Average | ☐ | ☐ | ☐ | ☐ |
| • Above average | ☐ | ☐ | ☐ | ☐ |
| **1.2 Reaction to risk question** | | | | |
| • Confident in answering question | ☐ | ☐ | ☐ | ☐ |
| • Hesitant, finds it difficult, isn't sure, don't know, 'I'll just put', guessing | ☐ | ☐ | ☐ | ☐ |
| • Don't know anything about the subject/no idea | ☐ | ☐ | ☐ | ☐ |
| • Never thought about it before | ☐ | ☐ | ☐ | ☐ |

| Question | Yes | Cancer in general | | Bowel cancer | | Breast cancer | | Prostate cancer | |
|---|---|---|---|---|---|---|---|---|---|
| **2. Reasons for beliefs/causes** | | | | | | | | | |
| • **Family history/genes** | | Me | People in general | Me | People in general | Me | People in general | Me | People in general |
| • Family history | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| a. FDR…….. | ☐ | ☐ | N/A | ☐ | N/A | ☐ | N/A | ☐ | N/A |
| b. SDR…….. | ☐ | ☐ | N/A | ☐ | N/A | ☐ | N/A | ☐ | N/A |
| • Family history increases risk | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Family history decreases risk | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention family history/genes (excluded leading qu about fh) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • has family history of other illness | ☐ | | | | | | | | |
| • **Health behaviours** | | | | | | | | | |
| • Diet increases risk (exclude chemicals in food) | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Diet decreases risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention diet | ☐ | | | | | | | | |
| • Lack of exercise increases risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Exercise decreases risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention exercise | ☐ | | | | | | | | |
| • Smoking increases risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Not smoking decreases risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention smoking | ☐ | | | | | | | | |
| • Alcohol increases risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Avoiding alcohol decreases risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention alcohol | ☐ | | | | | | | | |
| • Poor hygiene can increase risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Good hygiene can decrease risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

| Question | | Cancer in general | | Bowel cancer | | Breast cancer | | Prostate cancer | |
|---|---|---|---|---|---|---|---|---|---|
| • **Health behaviours cont.** | | Me | People in general | Me | People in general | Me | People in general | Me | People in general |
| • Doesn't mention hygiene | ☐ | | | | | | | | |
| • Having several partners can increase risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Having few partners can decrease risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention sexual partners | ☐ | | | | | | | | |
| • Being overweight can increase risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Maintaining a healthy weight can reduce risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention weight | ☐ | | | | | | | | |
| • Taking medications can increase risk (exclude HRT see 'physical wellbeing') | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Avoiding medications can decrease risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention medications | ☐ | | | | | | | | |
| • Taking illegal drugs can increase risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Avoiding illegal drugs can decrease risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention illegal drugs | ☐ | | | | | | | | |
| • Having had or having checks (e.g. mammogram) decreases risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Avoiding checks increases risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention checks | ☐ | | | | | | | | |

| Question | | Cancer in general | | Bowel cancer | | Breast cancer | | Prostate cancer | |
|---|---|---|---|---|---|---|---|---|---|
| • **Environmental** | | Me | People in general | Me | People in general | Me | People in general | Me | People in general |
| • Passive smoking increases risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Avoidance of passive smoking decreases risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention passive smoking | ☐ | | | | | | | | |
| • Chemicals in food or containers (tins) can increase risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Avoiding certain foods that contain chemicals etc. reduces risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention chemicals in food | ☐ | | | | | | | | |
| • Mobile phone masts increases risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Avoiding mobile masts decreases risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention mobile masts | ☐ | | | | | | | | |
| • Pollution increases risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Avoiding pollution decreases risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention pollution | ☐ | | | | | | | | |
| • Asbestos exposure increases risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Avoiding asbestos decreases risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention asbestos | ☐ | | | | | | | | |
| • Other | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • **Age** | | | | | | | | | |
| • Older age increases risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Older age decreases risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • All ages are at risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention age | ☐ | | | | | | | | |

| Question | | Cancer in general | | Bowel cancer | | Breast cancer | | Prostate cancer | |
|---|---|---|---|---|---|---|---|---|---|
| • **Physical wellbeing** | | Me | People in general | Me | People in general | Me | People in general | Me | People in general |
| • Symptoms/irregular bowel movements increase risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Feeling well/no known symptoms, bowels working well reduces risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention symptoms | ☐ | | | | | | | | |
| • Other health concern increases risk (e.g. weakened immune system) | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Other health concern reduces risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention other health concern | ☐ | | | | | | | | |
| • Hormonal factors (HRT, breast feeding, children) increase risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Hormonal factors (HRT, breast feeding, children) decrease risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention hormonal factors | ☐ | | | | | | | | |
| • Having had cancer increases risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Not having had cancer reduces risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention personal history of ca | ☐ | | | | | | | | |

| Question | | Cancer in general | | Bowel cancer | | Breast cancer | | Prostate cancer | |
|---|---|---|---|---|---|---|---|---|---|
| • **Psychological factors** | | Me | People in general | Me | People in general | Me | People in general | Me | People in general |
| • Hope/trust/feel won't get it | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention hope/trust/feel won't get it | ☐ | | | | | | | | |
| • Stress increases risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Avoiding stress reduces risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention stress | ☐ | | | | | | | | |
| • Mind/body increases e.g. positive thinking | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Mind/body decreases | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention mind/body | ☐ | | | | | | | | |
| • Trigger e.g. shock or life event increases risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Avoiding a trigger can reduce risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention triggers | ☐ | | | | | | | | |
| • **Chance** | | | | | | | | | |
| • Chance/fate/luck increases risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Chance/fate/luck reduces risk | | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| • Doesn't mention chance/fate/luck | ☐ | | | | | | | | |
| • **Don't know** | | | | | | | | | |
| • Doesn't know reasons for risk judgment | | ☐ | | ☐ | | ☐ | | ☐ | |

| Question | |
|---|---|
| **4. Experience** | |
| • Has friend(s) who have had cancer (including non blood relatives) | ☐ |
| • Doesn't have friend (s) who have had cancer | ☐ |
| • Doesn't mention friends who have had cancer | ☐ |
| • Has read about cancer in media/leaflets or seen on TV | ☐ |
| • Hasn't read about cancer in media | ☐ |
| • Doesn't mention media/TV | ☐ |
| **5. Model of cancer** | |
| • Cancer seen as one disease | ☐ |
| • Cancer seen as different diseases | ☐ |
| **6. Functional aspect of risk** | |
| • Feeling at risk has changed behaviour | ☐ |
| • Feeling at risk hasn't changed behaviour | ☐ |
| • Doesn't mention functional risk | ☐ |

Appendix IX: Letter from GP to participants used in Study 6

**Nicholas Bradley, M.R.C.G.P.**
**David Hilton, M.R.C.G.P.**
**Stephen Vercoe, M.R.C.G.P.**
**Leo Clarke, M.R.C.G.P.**
**Gillian Stowell, M.R.C.G.P.**

**Ide Lane Surgery**
**Alphington**
**Exeter**
**EX2 8UP**

Date: 6th April 2004

The Bowel Cancer Survey

Your General Practice is working with University College London and Peninsula Medical School to look at people's views about bowel cancer. Screening for bowel cancer will be introduced in the UK in the next few years for men and women and we are looking at what people think about bowel cancer. There are more details on the enclosed information sheet.

**You do not have to take part in this study,** but if you do decide to take part then all you have to do is fill in the enclosed questionnaire, and send it back in the FREEPOST (no stamp required) envelope. The questionnaire takes about 15 minutes to fill out. If we have not received a questionnaire from you within 2 weeks, we will send you another as a reminder.

We will not give you feedback on your responses to the questions. If you are concerned about your bowel symptoms then please contact your GP.

If you would like to find out more about this study, then please call Katie Robb (a member of the research team) on

Thank you for your help.

Dr Leo Clarke

Appendix X: Information sheet used in Study 6

GP letterhead

# The Bowel Cancer Survey

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Discuss it with your friends and relatives if you wish. Ask us if there is anything that is not clear or if you would like more information.

Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Medical research and you'. This leaflet gives more information about medical research and looks at some questions you may want to ask. A copy may be obtained from CERES, PO Box 1365, London, N16 0BW.

Thank you for reading this.

**What is the purpose of the study?**
Screening for bowel cancer will be introduced in the UK in the next few years. As part of our preparatory research we would like to find out people's views on bowel cancer.

**Why have you been chosen?**
Patients at your GP practice between the ages or 45-65 years have been randomly selected to take part in this study. We are interested in finding out about people's views on bowel cancer and we would like to invite you to fill out our questionnaire.

**What will the study involve?**
With this letter you will find a questionnaire booklet. Most people take around 15 minutes to complete the questionnaire. Please answer as many of the questions as you can and return the questionnaire to us in the FREEPOST (no stamp needed) envelope provided. Completing and returning the envelope will be taken as an indication of your consent to take part in the study. Once you have sent back the questionnaire you will not be required to do anything further and we will not contact you again in relation to this study.

**Confidentiality**
All information that you provide is strictly confidential and only the research team will have access to it. Only group information will be given in any published outcomes from the study, with no indication of any participant's identity.

You may notice that the questionnaire has an ID number in the top right hand corner. The only reason for including this is so that we can identify who has and has not returned the

questionnaire. If you have not returned your questionnaire to us within 2 weeks we will send you another questionnaire as a reminder. The information on your questionnaire WILL NOT be linked to your name. You WILL NOT receive any feedback on your responses to the questionnaire from the research team or your GP.

**Do I have to take part?**
It is up to you to decide whether or not to take part. Your decision will not affect the standard of care you may receive now or in the future.

**What do I do now?**
If you would like to take part then please complete the questionnaire booklet and return it in the FREEPOST (no stamp needed) envelope.

**Further information about the study**
If you would like to obtain further information about the study please contact:

**Katie Robb**
**Cancer Research UK Health Behaviour Unit**
**University College London**
**2-16 Torrington Place**
**London WC1E 6BT**

This study is funded by Cancer Research UK and the Medical Research Council. It is intended that the results of the research will be published in a medical journal in about 2-3 years time. It is important to point out that no volunteers included in the research will be able to be identified from any report or publication. However, if you would like a copy of the published results of the research please contact us at the address given above and we will be happy to send them to you.

## The aim of this research is to improve screening services for men and women in the future

Appendix XI: Reminder letter used in Study 6

**St. Leonard's Medical Practice**

34 Denmark Road Exeter Devon EX1 1SF

Appointments 01392 201791
Health Visitor 01392 278005
Enquiries 01392 201790

| Dr Philip Evans | Dr Pip Hayes | Dr Adrian Freeman | Dr Harriet Dickson | Dr Alex Harding |
|---|---|---|---|---|
| MPhil FRCGP DRCOG | MRCGP DTMH DRCOG | MMedSci FRCGP | MRCGP MRCP DRCOG | MRCGP DRCOG DCH |

Date: 24th May 2004

## The Bowel Cancer Survey

**A few weeks ago, we wrote to you about this survey. As we do not appear to have received your reply yet, we are sending you another questionnaire in case the first has been mislaid.**

Just to remind you, your General Practice is working with University College London and Peninsula Medical School to look at people's views about bowel cancer. Screening for bowel cancer will be introduced in the UK in the next few years for men and women and we are looking at what people think about bowel cancer. There are more details about the survey on the enclosed information sheet.

**You do not have to take part in this study,** but if you do decide to take part then all you have to do is fill in the enclosed questionnaire, and send it back in the FREEPOST (no stamp required) envelope. The questionnaire takes about 15 minutes to fill out.

We will not give you feedback on your responses to the questions. If you are concerned about your bowel symptoms then please contact your GP.

If you would like to find out more about the project, then please call Katie Robb (a member of the research team) on **020 7679 6644**.

**If you have already sent your reply, or if you do not wish to take part in this survey, please accept our apologies and ignore this reminder.**

Thank you very much for your help.

INVESTOR IN PEOPLE

Appendix XII: Questionnaire used in the two intervention groups in Study 6.

# The Bowel Cancer Survey

This survey is designed to find out about your views on bowel cancer. Please be as honest as possible; there are no right or wrong answers.

All the replies we receive will be anonymous and confidential, and will be used for research purposes only.

**Please answer <u>all</u> the questions. Your answers are very important to our research and we are grateful for your help with this survey.**

**So please fill in this questionnaire and return it in the enclosed envelope. No stamp required.**

If you have any questions please contact:

Katie Robb
Cancer Research UK Health Behaviour Unit
Epidemiology and Public Health
University College London
2-16 Torrington Place
London WC1E 6BT
Tel: 020 7679 6644

**<u>PLEASE READ THE ENCLOSED LEAFLET "Bowel Cancer: The facts" BEFORE FILLING OUT THE QUESTIONNAIRE</u>**

| | | |
|---|---|---|
| **Have you read the leaflet "Bowel Cancer: The facts"?** | Yes ☐ | No ☐ |

FIRST, SOME QUESTIONS ABOUT YOUR HEALTH AND ATTITUDES Please tick your answers

**Would you say that for someone of your age your own health in general is:**

| Excellent | Good | Fair | Poor |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |

## BOWEL CANCER

**Compared to others of the same sex and age, my chances of getting bowel cancer are:**

| Much below average | Below average | Average | Above average | Much above average | Have had bowel cancer |
|---|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Why have you rated your chance of getting bowel cancer in this way?**

_____

_____

**As a percentage what do you think your chances are of getting bowel cancer?**

_____% (from 0% to 100% - where 0 means you definitely won't get cancer and 100 means you definitely will get cancer)

**How worried are you about getting bowel cancer?**

| Not worried at all | A bit worried | Quite worried | Very worried | Have had bowel cancer |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |

## ALL CANCERS

**Compared to others of the same sex and age, my chances of getting any cancer are:**

| Much below average | Below average | Average | Above average | Much above average | Have had cancer |
|---|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

## BREAST CANCER (WOMEN ONLY)

**Compared to other women my age, my chances of getting breast cancer are:**

| Much below average | Below average | Average | Above average | Much above average | Have had breast cancer |
|---|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

## PROSTATE CANCER (MEN ONLY)

**Compared to other men my age, my chances of getting prostate cancer are:**

| Much below average | Below average | Average | Above average | Much above average | Have had prostate cancer |
|---|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

1

**We would like to know how often people get these bowel symptoms and bowel problems. In the LAST THREE MONTHS have you...**

| | No | Occasionally | Frequently |
|---|---|---|---|
| been constipated? | ☐ | ☐ | ☐ |
| had haemorrhoids (piles) | ☐ | ☐ | ☐ |
| had diarrhoea? | ☐ | ☐ | ☐ |
| been troubled with wind? | ☐ | ☐ | ☐ |
| had pains in the abdomen (gut)? | ☐ | ☐ | ☐ |
| had bowel incontinence? | ☐ | ☐ | ☐ |
| noticed blood in your stools? | ☐ | ☐ | ☐ |

**PLEASE NOTE:** If you have symptoms persistently, you should go to your GP for advice.

**Have you ever been diagnosed with any of these bowel problems?**

| | No | Yes |
|---|---|---|
| Irritable bowel | ☐ | ☐ |
| Diverticular disease | ☐ | ☐ |
| Ulcerative colitis | ☐ | ☐ |
| Crohn's disease | ☐ | ☐ |
| Abdominal hernia | ☐ | ☐ |
| **Have you ever had your bowel or colon examined by a doctor or nurse?** | ☐ | ☐ |

**Have any members of your family (blood relatives, not relatives by marriage) had bowel cancer?**

| | Yes | No | Don't know | | Yes | No | Don't know | Not applicable |
|---|---|---|---|---|---|---|---|---|
| mother | ☐ | ☐ | ☐ | son (s) | ☐ | ☐ | ☐ | ☐ |
| father | ☐ | ☐ | ☐ | daughter (s) | ☐ | ☐ | ☐ | ☐ |
| mother's mother | ☐ | ☐ | ☐ | sister (s) | ☐ | ☐ | ☐ | ☐ |
| mother's father | ☐ | ☐ | ☐ | brother (s) | ☐ | ☐ | ☐ | ☐ |
| father's mother | ☐ | ☐ | ☐ | Other (please state) | ☐ | ☐ | ☐ | ☐ |
| father's father | ☐ | ☐ | ☐ | _____ | | | | |

**Have any of your close friends had bowel cancer?**

| Yes | No | Don't know |
|---|---|---|
| ☐ | ☐ | ☐ |

**If yes, how many close friends?**_____

**Have any members of your family or close friends had breast cancer?**

| | Yes | No | Don't know | |
|---|---|---|---|---|
| family | ☐ | ☐ | ☐ | **If yes, how many family members?**_____ |
| close friends | ☐ | ☐ | ☐ | **If yes, how many close friends?**_____ |

**Have any members of your family or close friends had prostate cancer?**

| | Yes | No | Don't know | |
|---|---|---|---|---|
| family | ☐ | ☐ | ☐ | **If yes, how many family members?**_____ |
| close friends | ☐ | ☐ | ☐ | **If yes, how many close friends?**_____ |

**Have any members of your family or close friends had any other type of cancer (apart from bowel, breast and prostate)?**

| | Yes | No | Don't know | |
|---|---|---|---|---|
| family | ☐ | ☐ | ☐ | **If yes, how many family members?**_____ |
| close friends | ☐ | ☐ | ☐ | **If yes, how many close friends?**_____ |

## YOUR BELIEFS ABOUT BOWEL CANCER

**Please indicate how much you agree or disagree with the following statements:**

| | Strongly disagree | Disagree | Not sure | Agree | Strongly agree |
|---|---|---|---|---|---|
| I have a clear picture of what bowel cancer is | ☐ | ☐ | ☐ | ☐ | ☐ |
| There are things I can do to control whether I get bowel cancer or not | ☐ | ☐ | ☐ | ☐ | ☐ |
| When found early, bowel cancer can be cured | ☐ | ☐ | ☐ | ☐ | ☐ |
| People can still be at risk of bowel cancer even if no one in the family has it | ☐ | ☐ | ☐ | ☐ | ☐ |
| Regular exercise can reduce the risk of bowel cancer | ☐ | ☐ | ☐ | ☐ | ☐ |
| Men are at slightly higher risk of getting bowel cancer than women | ☐ | ☐ | ☐ | ☐ | ☐ |
| Smoking increases the risk of developing bowel cancer | ☐ | ☐ | ☐ | ☐ | ☐ |
| People can still be at risk of bowel cancer even if they have no symptoms | ☐ | ☐ | ☐ | ☐ | ☐ |
| Being overweight or obese increases the risk of bowel cancer | ☐ | ☐ | ☐ | ☐ | ☐ |
| A diet high in red and processed meat increases the risk of bowel cancer | ☐ | ☐ | ☐ | ☐ | ☐ |
| Environmental pollution may increase the risk of bowel cancer | ☐ | ☐ | ☐ | ☐ | ☐ |
| Breathing in other people's cigarette smoke (passive smoking) can increase the risk of bowel cancer | ☐ | ☐ | ☐ | ☐ | ☐ |
| The things that are added to food (e.g. additives and preservatives) may increase the risk of bowel cancer | ☐ | ☐ | ☐ | ☐ | ☐ |

| | Strongly disagree | Disagree | Not sure | Agree | Strongly agree |
|---|---|---|---|---|---|
| Stress may increase the risk of developing bowel cancer | ☐ | ☐ | ☐ | ☐ | ☐ |
| Bowel cancer is caused by a germ or a virus | ☐ | ☐ | ☐ | ☐ | ☐ |
| It is just chance that people get an illness like bowel cancer | ☐ | ☐ | ☐ | ☐ | ☐ |
| Bowel cancer can be triggered by a traumatic experience | ☐ | ☐ | ☐ | ☐ | ☐ |
| Bowel cancer can develop from polyps in the bowel | ☐ | ☐ | ☐ | ☐ | ☐ |
| Older people are more at risk of bowel cancer | ☐ | ☐ | ☐ | ☐ | ☐ |

THESE ARE SOME GENERAL QUESTIONS ABOUT YOUR MOOD AND OUTLOOK ON LIFE, BECAUSE WE KNOW THESE CAN AFFECT PEOPLE'S ATTITUDES TO THEIR HEALTH

**Please read each statement, and then mark the appropriate box for each question to indicate <u>how you feel right now</u>, at this moment**

| | Not at all | Somewhat | Moderately | Very much |
|---|---|---|---|---|
| I feel calm | ☐ | ☐ | ☐ | ☐ |
| I am tense | ☐ | ☐ | ☐ | ☐ |
| I feel upset | ☐ | ☐ | ☐ | ☐ |
| I am relaxed | ☐ | ☐ | ☐ | ☐ |
| I feel content | ☐ | ☐ | ☐ | ☐ |
| I am worried | ☐ | ☐ | ☐ | ☐ |

**Please indicate how much you agree with each of the following items by ticking the appropriate box:**

| | Strongly disagree | Disagree | Not sure | Agree | Strongly agree |
|---|---|---|---|---|---|
| In uncertain times, I usually expect the best | ☐ | ☐ | ☐ | ☐ | ☐ |
| If something can go wrong for me, it will | ☐ | ☐ | ☐ | ☐ | ☐ |
| I'm always optimistic about my future | ☐ | ☐ | ☐ | ☐ | ☐ |
| I hardly ever expect things to go my way | ☐ | ☐ | ☐ | ☐ | ☐ |
| I rarely count on good things happening to me | ☐ | ☐ | ☐ | ☐ | ☐ |
| Overall, I expect more good things to happen to me than bad | ☐ | ☐ | ☐ | ☐ | ☐ |

THESE ARE SOME QUESTIONS ABOUT BEHAVIOURS RELATED TO YOUR HEALTH

**SMOKING**

**Please tick the box that best describes your smoking habits:**

Never-smoker/ non-smoker ☐ Ex-smoker ☐ Smoker ☐

**If you are a smoker, how many cigarettes do you usually smoke?** ☐☐ **per day** **OR** ☐☐ **per week**

**DIET**

**On a typical day how many servings of the following would you eat?**

| | **Please enter the number of servings/units in the box** |
|---|---|
| **Fruit (fresh, frozen or canned)?** For example, one apple counts as one serving. | ☐ |
| **Vegetables (including salad, but excluding potatoes)?** For example a handful of carrots counts as one serving. | ☐ |
| **Red meat (including beef, pork, lamb)?** For example a chop counts as one serving. | ☐ |
| **In a typical week how many units of alcohol would you consume?** For example a unit is a small glass of wine or half a pint of lager. | ☐ |

**PHYSICAL ACTIVITY**

**During the past 7 days, on how many days did you:**

Engage in vigorous activity that caused you to breathe much harder than normal and sweat (e.g. swimming, jogging, aerobics, football)?

_____days per week _____minutes per day ☐Don't know/not sure

Engage in moderate activity that caused you to breathe somewhat harder than normal (e.g. cycling, gardening, dancing, brisk walking)

_____days per week _____minutes per day ☐Don't know/not sure

NOW SOME QUESTIONS ON SCREENING AND SEEKING MEDICAL ATTENTION

How important do you think it is that this country introduces a nationwide bowel screening programme?

Very important ☐ Important ☐ Not sure ☐ Unimportant ☐ Very unimportant ☐

If you were invited to have a bowel screening test, would you take up the offer?

Yes, definitely ☐ Yes, probably ☐ Probably not ☐ Definitely not ☐

If you noticed a change in your bowel habits which lasted for more than two weeks would you.....

| Go to your GP to have it checked out | Wait to see if it cleared up | Ignore it and hope it went away by itself | Seek advice from a family member or a friend |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |

If you noticed blood in your bowel motions (stool) for more than two weeks would you.....

| Go to your GP to have it checked out | Wait to see if it cleared up | Ignore it and hope it went away by itself | Seek advice from a family member or a friend |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |

SOME QUESTIONS ABOUT YOU AND YOUR FAMILY TO HELP US ANALYSE THE SURVEY

**What is your marital status?**

| Single | Married | Cohabiting / living with partner | Divorced / separated | Widowed |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |

**How many children do you have?**

| None | 1 | 2 | 3 | More than 3 |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |

**What is your ethnic group?**

| White | Mixed | Asian or Asian British | Black or Black British | Chinese | Other | Do not wish to answer |
|---|---|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Please tick the box which best describes your living arrangement:**

| Rent from local authority | Rent from private landlord | Own home | Other |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |

| **Does your household have a car or van?** | No | Yes, 1 | More than 1 |
|---|---|---|---|
| | ☐ | ☐ | ☐ |

**Are you currently:**

- ☐ employed full-time
- ☐ employed part-time
- ☐ unemployed
- ☐ full-time homemaker
- ☐ retired
- ☐ student
- ☐ disabled or too ill to work

**What is the highest level of educational or professional qualification you have obtained?**

- ☐ GCSE/O-level/CSE
- ☐ Vocational qualifications (e.g. NVQ1+2)
- ☐ A-level or equivalent (e.g. NVQ3)
- ☐ Bachelor Degree or equivalent (e.g. NVQ4)
- ☐ Other
- ☐ No formal qualifications
- ☐ Still studying

| Do you ever use the Internet? | Yes ☐ | No ☐ | Don't know ☐ |
|---|---|---|---|

**How tall are you? _____ft. _____inches OR _____cm**

**How much do you weigh? ____stone ____pounds OR _____kgs**

FURTHER COMMENTS

**Did you find completing this questionnaire...?**

| Very easy ☐ | Quite easy ☐ | Quite difficult ☐ | Very difficult ☐ |
|---|---|---|---|

We are very interested in hearing your thoughts on any aspect of this questionnaire, so please write any further comments you have in the box below.

**THANK YOU VERY MUCH FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE.**
**YOUR ANSWERS ARE VERY IMPORTANT TO OUR RESEARCH**

# Appendix XIII: Ethical approval for Study 6

NHS

**North and East Devon LREC**
Department of Research Ethics
and Medical Affairs
Old Kenn Ward
Royal Devon & Exeter Hospital
Barrack Road
Exeter EX2 5DW

Tel: 01392 402369
Fax: 01392 402369

**Our Ref.: TJ/BCT/2004/1/4**

06 January 2004

Kathryn Robb
UCL Health Behaviour Unit
Epidemiology & Public Health
2-16 Torrington Place
London WC1E 6BT

Dear Kathryn

**Study 2004/1/4 : Survey on beliefs about bowel cancer**

Thank you for your letter of 22nd December about your proposed study. I have looked at the questionnaire, which you propose to use, and the information sheet that you would send to participants. Since you intend to use only 'healthy' volunteers, then I do not think you need formal approval. I would regard what you do as, in one sense, service evaluation.

Kind regards
Yours sincerely

Dr Terry Jones
Chairman
North and East Devon LREC

Appendix XIV: Research Governance approval for Study 6.

Exeter NHS
Primary Care Trust

Kathryn Robb
Department of Epidemiology and Public Health
Gower Street Campus
University College London
2-16 Torrington Place
LONDON
WC1E 6BT

RMG/RH/VF

5th March 2004

Dear Kathryn Robb

**RE: PCT0103 THE BOWEL CANCER SURVEY: THE EFFICACY OF PROVIDING SIMPLE INFORMATION ABOUT BOWEL CANCER RISK ON PERCEIVED RISK AND INTEREST IN ATTENDING SCREENING**

I have reviewed the Trust Research Governance file for your study and I am happy to give approval on behalf of the Trust.

**Adverse Events**
Can I remind you that you must report to the Research Governance Unit any serious adverse event occurring during the study, quoting the study reference number. This requirement is in addition to informing the Chairman of the Local Ethics Committee.

**Outcome and publications**
You must also submit to the Research Governance Unit a final outcome report on completion of your study. If your study takes longer than a year annual reports on progress will be needed. If you publish please send copies to the Research Governance Unit in the PGMC, Barrack Road, Exeter, EX2 5DW for inclusion in our Research Governance file for your study.

**Research Governance**
I would like to take this opportunity to remind you of your responsibilities as an NHS researcher. These are:

1. Work must be carried out in line with the new Research Governance Framework for Health and Social Services, which details the responsibilities for everyone involved in research
2. The Data Protection Act 1998 requires you to follow the eight principles of "good information handling"
3. You must be aware of, and comply with, Health and Safety standards in relation to your research.



WHF 002

More information about all these responsibilities can be found on the Primary Care Page of the RD&E web-page at **www.exeterhospitalsresearch.org.uk**

With best wishes for a successful study.

Yours sincerely

Nick Bradley
Research Governance Lead
Exeter PCT

cc. Dr Terry Jones, Chairman of North and East Devon LREC
Ruth Hall, R & D Manager, Exeter PCT

## The future: Bowel screening

The Secretary of State for Health announced in November 2002 his commitment to introduce a nationwide bowel cancer screening programme. The screening programme will be for men and women around the age of 60 and will be similar to the breast screening programme which already exists for women. The Government is considering what type of bowel screening to introduce. The two options are:

- **Faecal occult blood test (FOBT) or stool test.** This test examines a small sample of your stool/bowel motion, for early signs of cancer.
- **Flexi-scope test.** This test involves an experienced nurse inserting a thin tube into the back passage and painlessly removing any polyps. Removing these polyps helps to prevent bowel cancer.

**What are the symptoms of bowel cancer?**

Symptoms may include:

- Blood or mucus in the stools
- Change in bowel habits lasting more than two weeks
- Losing weight
- Pain in the stomach area
- Straining feeling in the rectum

These symptoms may well be due to other causes. The most common cause for bleeding, for example, is piles (haemorrhoids). However, **people who notice any symptoms should see their doctor.** The earlier bowel cancer is detected, the better the chance of cure.

## Any questions?

If you have any questions about the information in this leaflet please feel free to ring **Katie Robb on: 020 7679 6644** or e-mail: k.robb@ucl.ac.uk.





# Bowel cancer:

# The facts

## The bowel cancer survey

University College London

MRC Medical Research Council

UCL

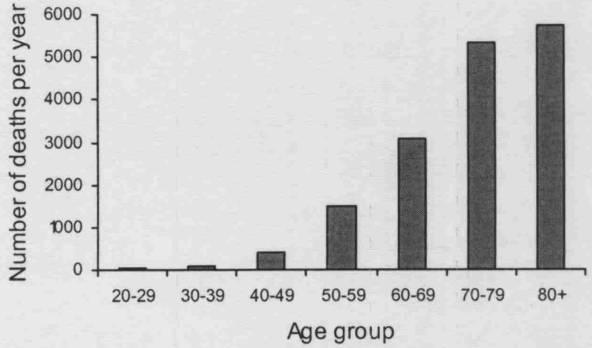
# Bowel cancer: The facts

- Bowel cancer is the second most common cause of cancer death.
- Over 16,000 men and women die each year in the UK from bowel cancer.
- In the UK it kills one person every half an hour.
- Bowel cancer develops from growths known as polyps.
- Polyps are harmless at first, but over time some can become cancers.

# Who is most at risk?

## Older people are at higher risk

- The older you are, the higher your risk.




## People with a less healthy lifestyle are more at risk

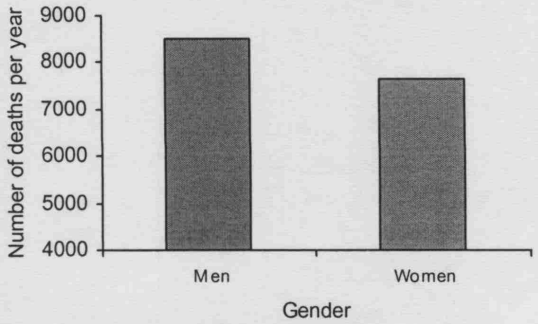
- A diet high in red and processed meat increases the risk of the disease.
- Not exercising regularly increases your risk.
- Smoking increases your risk of bowel cancer.
- Being overweight or obese increases your risk.





## Men are at higher risk

- Bowel cancer is slightly more common in men than in women.




## Does it run in families?

- Yes and no.
- If you have 2 close relatives with bowel cancer your risk is higher than average.
- If you have only 1 relative your risk is slightly higher than average.
- But everyone is at risk, 85% of bowel cancer cases do not have a family history of the disease.

## What if I have no symptoms?

Even people who feel well may still be at risk of getting bowel cancer.

- In the early stages there usually are no signs or symptoms of the illness.
- This means people can still be at risk, even if they feel fit and healthy.